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Disability & Obesity in Canadian Children Network

ProFILE lab

Fostering positive weight-related conversations: Evidence and real-life learnings from the heart of care

A Knowledge Translation Casebook for Healthcare Professionals

Amy McPherson, PhD, CPsychol (UK)
Senior Scientist, Bloorview Research Institute
Associate Professor, University of Toronto

Bloorview
RESEARCH INSTITUTE

No boundaries

Objectives

1. To understand the currently available evidence supporting the Casebook
2. To learn about the Casebook's content and resources
3. To identify how the KT Casebook may be integrated into clinical practice

Background

- Leading paediatric societies recommend that children 2 years+ have their body mass index (BMI) monitored (DoC & CPS, 2010)
- Discussions of healthy lifestyles are also important to establish healthy behaviours early in life (Barlow et al, 2007)
- Weight stigma is common in healthcare
  - 65% health trainees had heard/witnessed HCPs making negative comments/jokes about patients with obesity (Puhl et al, 2013)

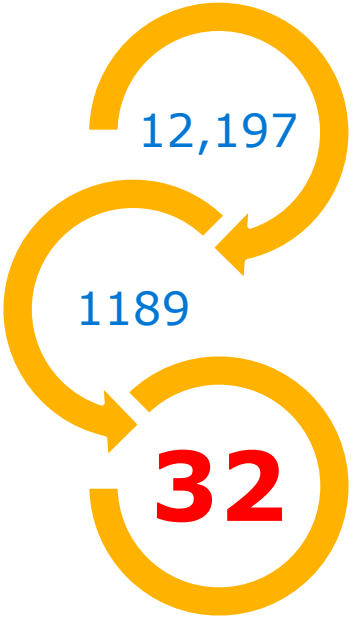
What's does the evidence say?

- Scoping review methodology
- Inclusion criteria:

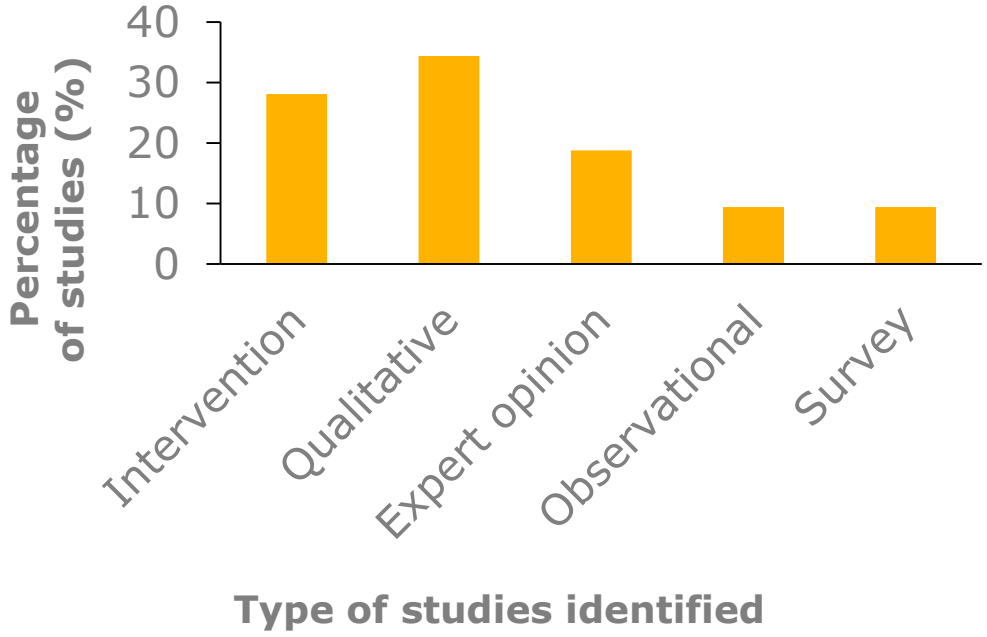
i. ≤18 years of age and/or parents;

ii. Communication about healthy weight, overweight, obesity or healthy/active living; and

iii. Formal healthcare setting



Included studies (n=32)



(i) Guideline dissemination
(ii) Therapeutic communication techniques
(iii) Lived experiences

obesity reviews

doi: 10.1111/obr.12485

Communicating with children and families about obesity and weight-related topics: a scoping review of best practices

A. C. McPherson,[1,2] J. Hamilton,[3,4] S. Kingsnorth,[1,5] T. J. Knibbe,[1] M. Peters,[1] J. A. Swift,[6] K. Krog,[7,8] L. Chen,[9] A. Steinberg[10] and G. D. C. Ball[11]

- Start conversations early in a child's life and discuss regularly [38-40, 47, 55].
- Involve all relevant stakeholders (child, parents, other family members where appropriate) in discussions [38, 41, 43-45, 55].
- Approach the topic of weight and obesity in terms of growth and health [46, 47].
- Avoid idioms or euphemisms to describe overweight and obesity, and clarify meanings of any terms used [17, 38, 48, 53, 55].
- Explore with the family what terminology they prefer to use [17, 42].
- Communicate trust and respect by using active listening, exploring family perspectives through open questions, being collaborative and strengths- based [12, 36, 37, 50, 53, 54].
- Motivational interviewing techniques may be helpful in engaging children and parents [44, 45, 57-59, 61-63], but a more robust body of evidence is required to explicate its efficacy and exact causal mechanisms.

ORIGINAL ARTICLE

"Fat is really a four-letter word": Exploring weight-related communication best practices in children with and without disabilities and their caregivers

A. C. McPherson ✉, T. J. Knibbe, M. Oake, J. A. Swift, N. Browne, G. D. C. Ball, J. Hamilton

- Broad endorsement of guiding principles → gap between desired and actual experiences
- Consider:
  - Who should be involved
  - When/how often to raise the topic
- Similarities across samples (disabilities/non disabilities)
  - Some specific differences (e.g. ASD)
  - Positive, strengths- based approaches welcomed

What about kids with disabilities?

Research Paper

Communicating about obesity and weight-related topics with children with a physical disability and their families: spina bifida as an example

Amy C. McPherson, Judy A. Swift, Michelle Peters, Julia Lyons, Tara Joy Knibbe, Paige Church, ...Show all

Pages 791-797 | Received 11 Sep 2015, Accepted 01 Mar 2016, Published online: 25 Mar 2016

Original Articles

A feasibility study using solution-focused coaching for health promotion in children and young people with Duchenne muscular dystrophy

Amy C. McPherson, Laura McAdam, Sarah Keenan, Heidi Schwellnus, Elaine Biddiss, Andrea DeFinney &

"Girls don't have big tummies": The experiences of weight-related discussions for children with autism spectrum disorders

Patrick Jachyra[1], Evdokia Anagnostou[1], Tara J Knibbe[2], Catharine Petta[1], Susan Cosgrove[1], Lorry Chen[1], Lucia Capano[1], Lorena Moltisanti[1] and Amy C McPherson

Considerations for children with disabilities

- Role of medication
- Long-term therapeutic relationships
- Fear of stigmatising child
- Body composition
- Priorities
- Expectations

Healthcare Professionals: Barriers to communicating about weight

- Time

- Priorities

- Training

- Child self-esteem

- Resources

- Confidence

(Barlow, 2002; Jelanian, 2003; Mikhailovich & Morrison, 2007)

Addressing the gap:
A Knowledge Translation (KT) Casebook

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What is a KT Casebook?

Presents a collection of information on a clinical topic by providing summaries of the research evidence (where available) and sharing the experiences of practicing healthcare professionals, children and families.

(Widger et al., 2013)

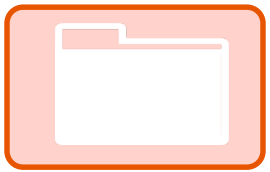
KT Casebook Aims

Research Evidence

- Provide the "best available" research evidence
- Highlight "best available" practices

Experiential Evidence

- Share unique perspectives and experiences of children, youth, families and healthcare professionals



Resources

- Provide suggestions, tools, resources and reasoning for practices

Our approach: Casebook development team

- Dr. Amy McPherson (PhD)
- Christine Provvidenza (MSc, R. Kin)
- Dr. Laura Hartman (PhD, OT)
- Susan Cosgrove (Family Leader)
- Julia Lyons (RN)
- Dr. Jill Hamilton (MD)
- Shannon Crossman (BFA)
- Dr. Evdokia Anagnostou (MD)

Our approach: Engaging end-users

Our approach: Stakeholder consultation + workshops

- Discuss, plan and design the casebook
- Facilitated through activities that promote thoughtful reflection and group discussion

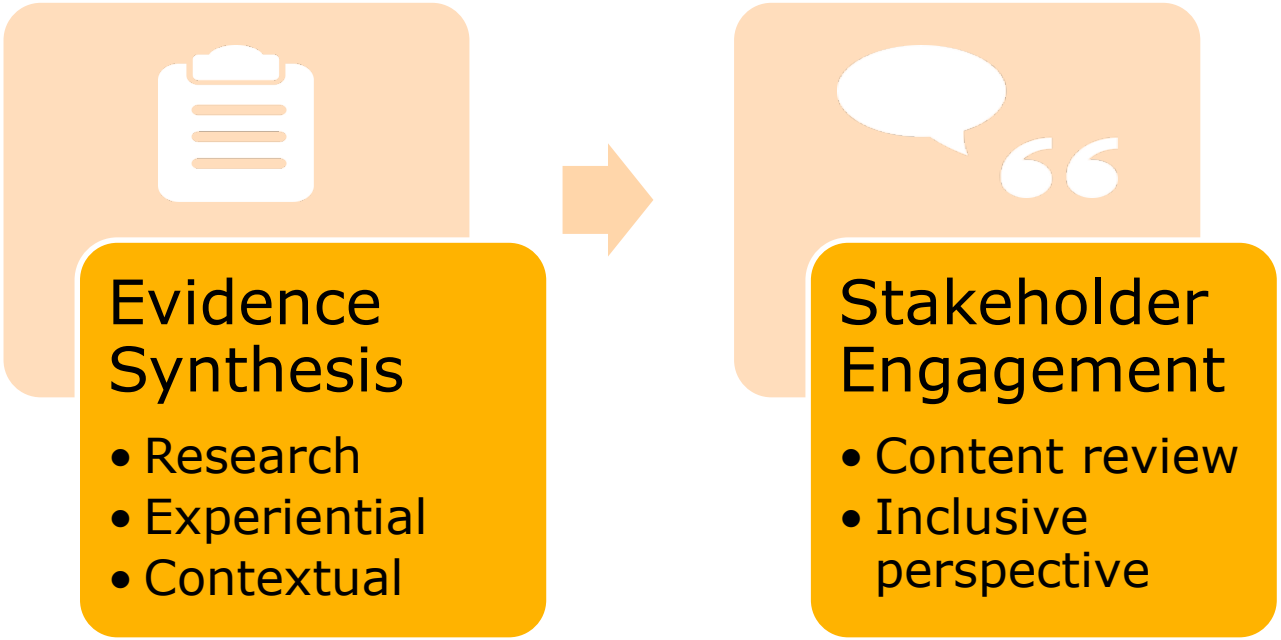
- Co-create materials for the casebook
- Facilitated through creative activities that will produce content for the casebook

Stakeholder consultation + workshops

Our approach: Stakeholder consultation + workshops

- Topic overview
- An introduction to Casebooks
- Capturing thoughts, feelings and hopes for weight-related conversations
- Overview of evidence and best practices
- Group co-creation of products, tools and resources

Our approach: Content development and review



Guiding the conversation: A KT Casebook

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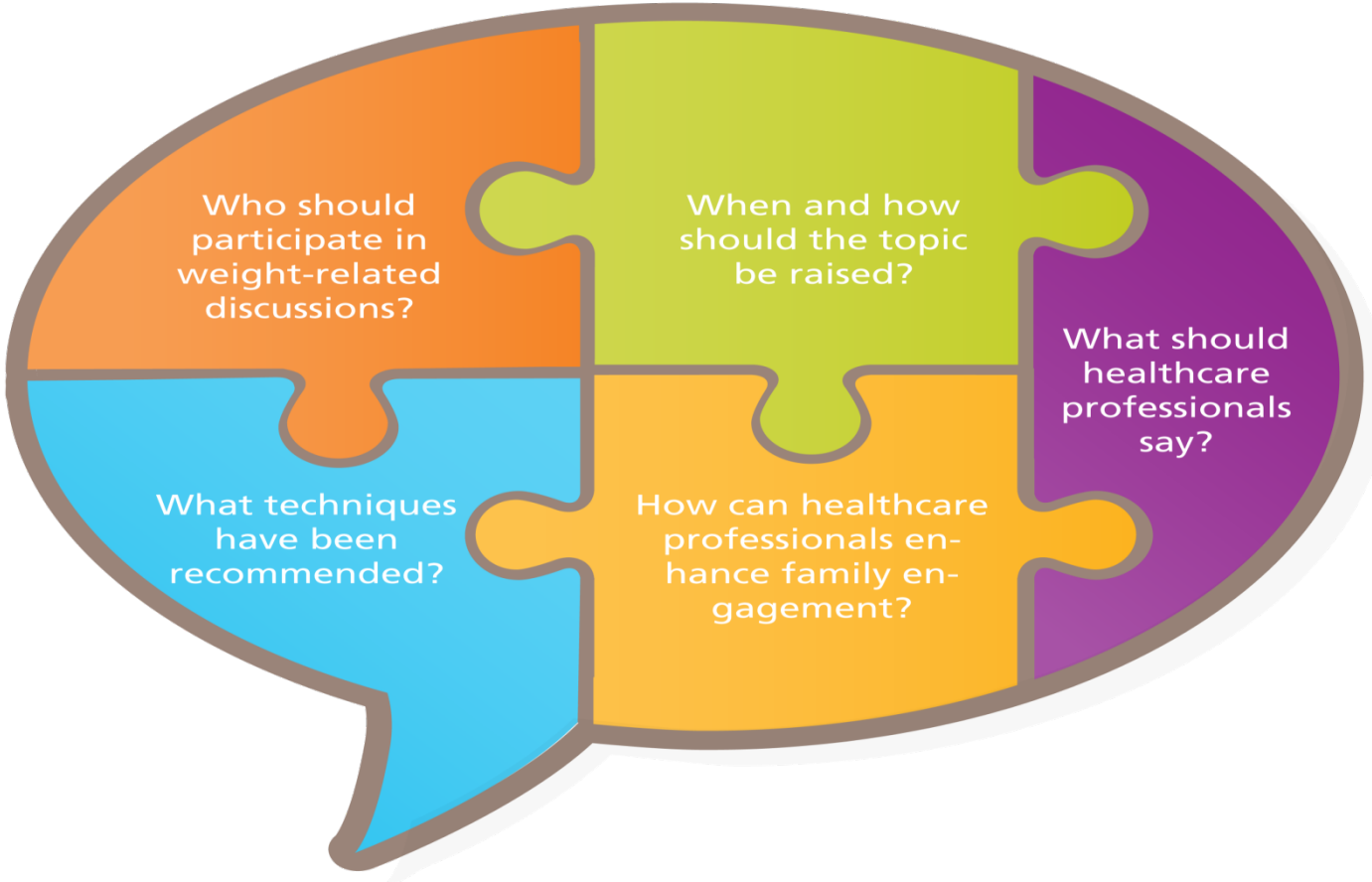
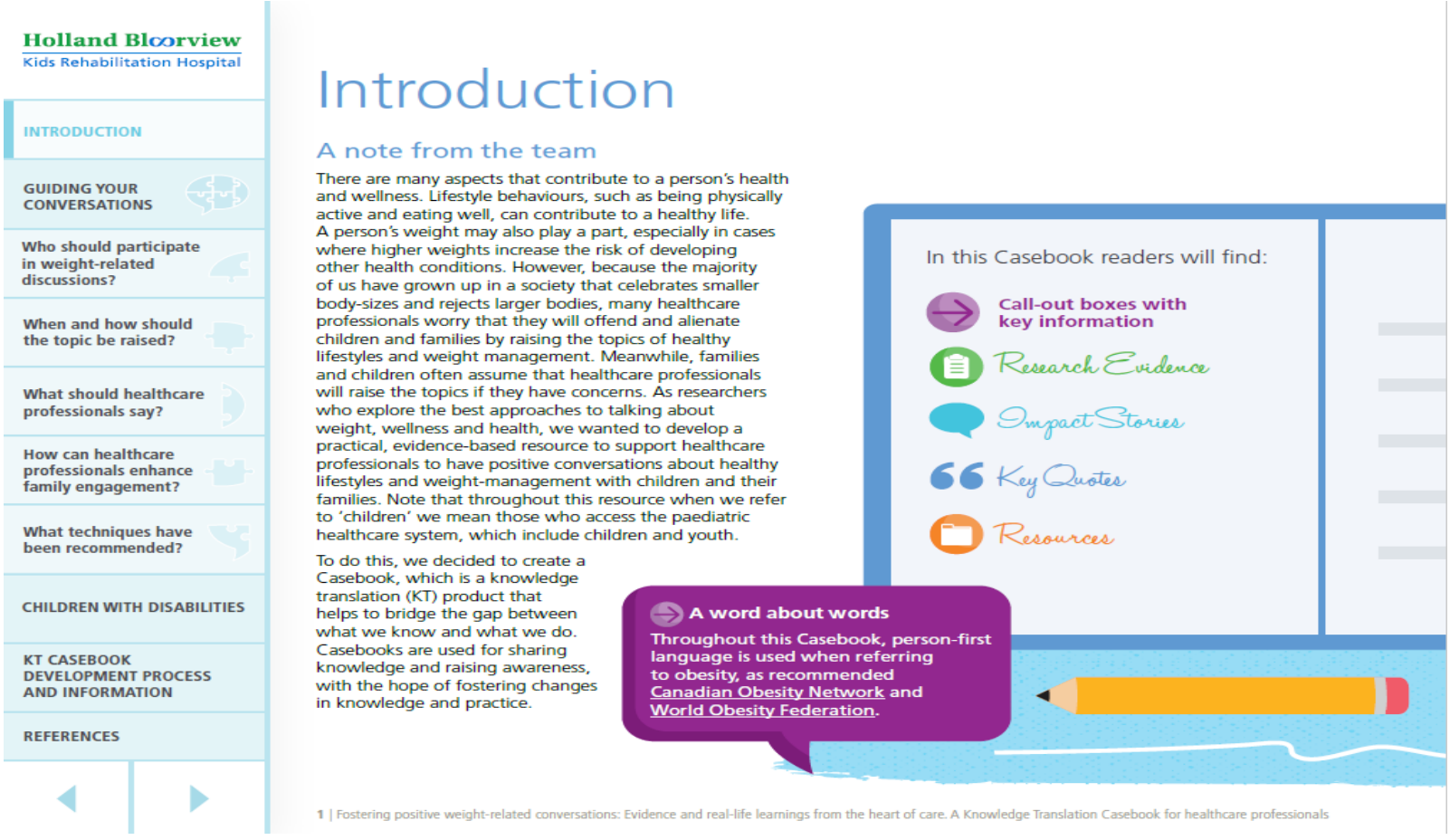
Guiding the conversations: 5 key questions



Casebook organization



Showcasing evidence

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There are many ways to involve children and families in weight-related conversations. Knowing who should be involved in the conversation early on and being respectful of their voices allows more meaningful conversations to take place.

Research Evidence

Consideration of the individual child should always be at the centre of discussions. Families should be consulted on who should be involved in the discussions. Some children may prefer discussions to occur initially with their families. Other children are happy to be included in weight-related discussions, especially as they near or enter adolescence.[19] Some families may benefit from inviting other members (e.g. grandparents) who provide regular care for the child to be part of the conversation. This approach can be helpful in creating home environments that will help to sustain healthy habits.[4, 20] While the best available literature generally supports the inclusion of all of the key stakeholders in discussions,[2] healthcare professionals should explore with each family how best to provide personalized care within their particular family context.

A summary of who should be involved in conversations is provided in Figure 2. Although evidence supports the involvement of a familiar, trusted healthcare professional in weight-related conversations, this may not always be possible. The ability to establish rapport, use appropriate language and adopt a respectful approach can all support positive conversations in this situation, and is often more important than engaging with a particular provider discipline (e.g., physician, dietitian).

Showcasing evidence

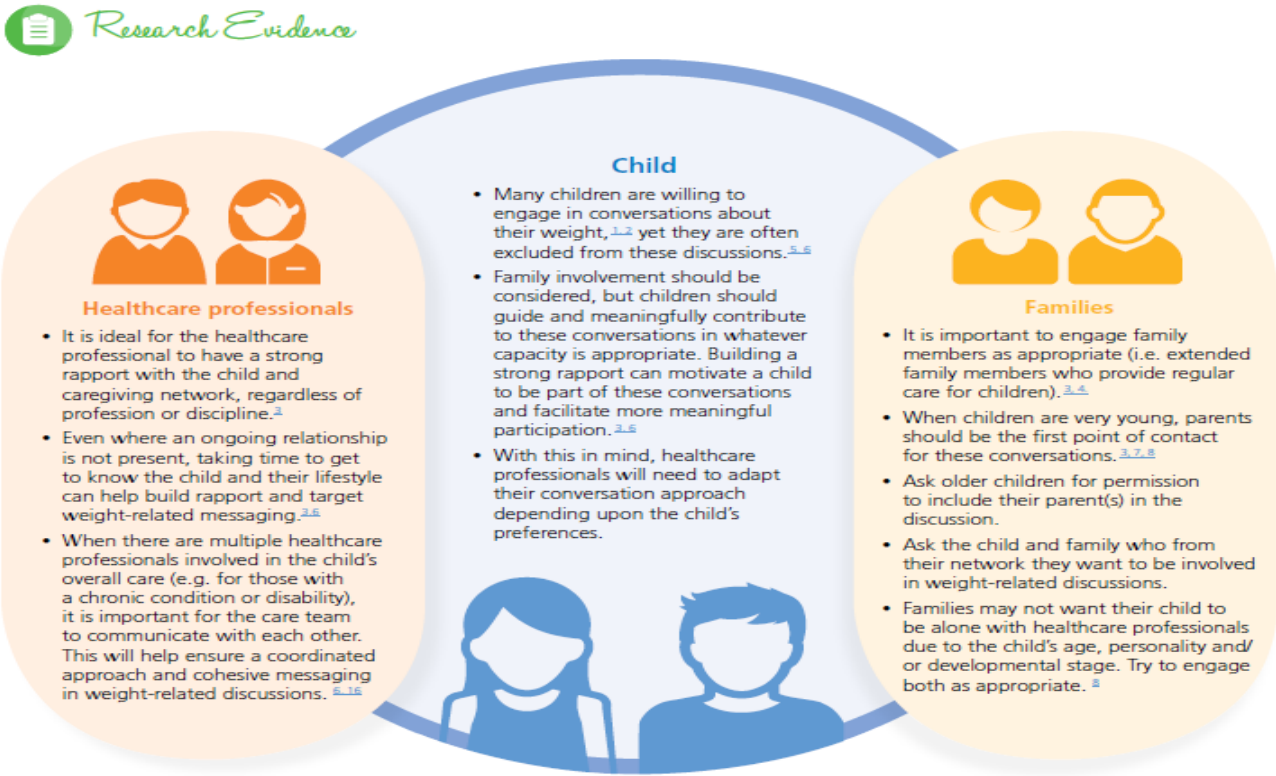


Figure 2. The 'who' of engaging in weight-related conversations

Sharing impact stories

Impact Story

Brenndon Goodman is a political science student at York University working towards an Honors Bachelor of Arts. He is a member of the public engagement committee for the Canadian Obesity Network and is a passionate voice for people living with obesity.

BRENNDON

What have been your past experiences of having conversations with healthcare professionals about your weight?

Every time I went to my doctor as a child, no matter the reason, I was bombarded with negative comments by my paediatrician about my obesity. By making every appointment related to my weight, I would dread going to the doctor. He would instill panic in my parents that caused them to put me on crash diets. By my teenage years, I stopped going to him altogether. Instead, I would go to walk-in clinics if I needed medical treatment.

> *I was once told that I would be dead before I reached 30 years. How would that help a 10 year old child?*

How did those encounters make you feel?

I felt horrible. I would be carted to dietitians and specialists around the city, many of whom would either try to scare the weight off me or have unrealistic dietary expectations for me on the first visit. I was once told that I would be dead before I reached 30 years. How would that help a 10 year old child? All of this culminated in a deep distrust of the medical system and its ability to deal with obese people in a productive and respectful manner. I would try and avoid medical help with my weight as much as possible.

How do you want to feel after discussing weight and wellness with your healthcare professionals?

I would like to feel empowered and confident that I can reach a healthier lifestyle myself and with the help of my doctor. I think that a person should leave a doctor's office in the right frame of mind and this is paramount for dealing with their situation. If the individual is not in the right place mentally and feeling good about themselves, it is highly unlikely that their weight loss journey will be a positive experience.

> *I would like to feel empowered and confident that I can reach a healthier lifestyle myself and with the help of my doctor.*

What advice do you have for healthcare professionals when having these conversations with children and/or families?

Children are not always ignorant to what is occurring to their body and their health. When I was 6 or 7 years old, I fully comprehended than I was much larger than the other kids and that it was unhealthy. I did not need to be reminded of this fact at every visit to the doctor and made to feel ashamed of myself. Ask the patient what lifestyle changes they are willing to make and which they believe that they will be able to follow through with - try not to tell them what changes they must make. Above all, don't try to scare a patient in an attempt to get them to change. Positive feedback always goes a long way when compared to negative scolding.

Sharing resources

WHEN GETTING THE CONVERSATION STARTED
Things to think about

DO

- Always ask permission to have the conversation. (e.g. see conversation starters for suggested wording).
- Use person-first language (e.g. "person with obesity").
- Make eye contact and talk to children and families equally.
- Ask children and families what is important to them to feel healthy and well.
- Listen.
- Affirm and acknowledge the child and family's responses, even if you don't agree with them. Seek common ground to move forward.
- Hold genuine interest in what children and families have to say.
- Make growth and healthy lifestyles a part of every consultation (as appropriate). This can help to de-stigmatize the topics.
- Talk about the benefits of healthy lifestyles and healthy home environments for children and the entire family.

DON'T

- Over-simplify the problem or solution (e.g. just move more, eat less, it's just a matter of will power).
- Assume the reasons for weight-related issues (e.g. they are not taking their health seriously).
- Assume that families are not already engaged in healthy behaviours.
- Be judgemental or use shame, blame or scare tactics.
- Leave a family without resources and next steps.
- Assume that families are ready, willing and able to make changes right away.

Resources

MI infographic

Check out this infographic developed by the American Council on Exercise highlighting key MI techniques.

Using MI in obesity prevention

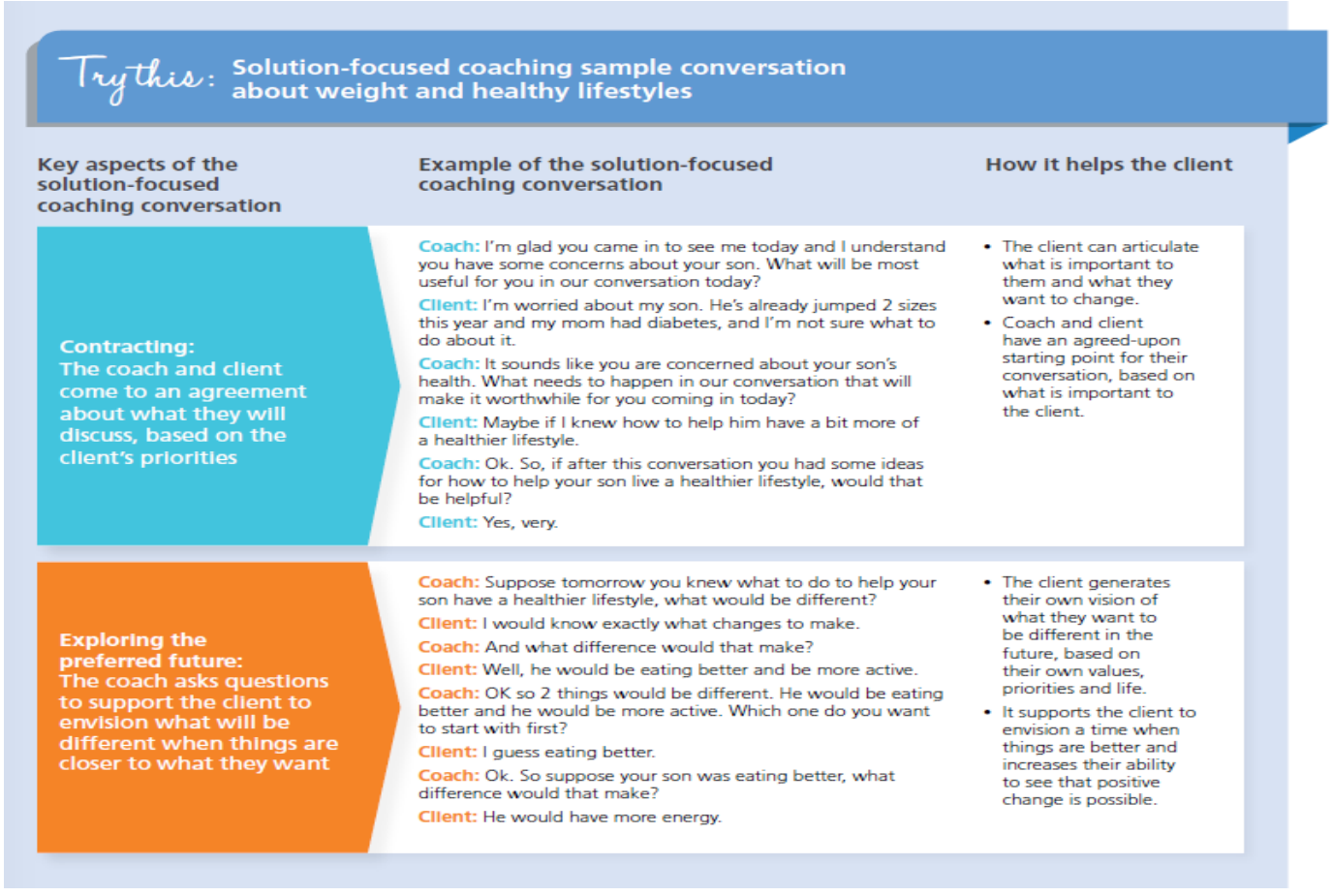
Barlow[4] discusses how to use MI through an example of an obesity prevention protocol. To review this protocol, see Table 4 of Barlow's open access paper.

MI App

The American Academy of Pediatrics Institute for Healthy Childhood Weight has a web and mobile app called "Change Talk: Childhood Obesity." This uses an interactive virtual practice environment to train paediatricians about the basics of MI.

Change Talk

Sharing resources



Try this: Solution-focused coaching sample conversation about weight and healthy lifestyles

Key aspects of the solution-focused coaching conversation	Example of the solution-focused coaching conversation	How it helps the client
Contracting: The coach and client come to an agreement about what they will discuss, based on the client's priorities	**Coach:** I'm glad you came in to see me today and I understand you have some concerns about your son. What will be most useful for you in our conversation today? **Client:** I'm worried about my son. He's already jumped 2 sizes this year and my mom had diabetes, and I'm not sure what to do about it. **Coach:** It sounds like you are concerned about your son's health. What needs to happen in our conversation that will make it worthwhile for you coming in today? **Client:** Maybe if I knew how to help him have a bit more of a healthier lifestyle. **Coach:** Ok. So, if after this conversation you had some ideas for how to help your son live a healthier lifestyle, would that be helpful? **Client:** Yes, very.	• The client can articulate what is important to them and what they want to change. • Coach and client have an agreed-upon starting point for their conversation, based on what is important to the client.
Exploring the preferred future: The coach asks questions to support the client to envision what will be different when things are closer to what they want	**Coach:** Suppose tomorrow you knew what to do to help your son have a healthier lifestyle, what would be different? **Client:** I would know exactly what changes to make. **Coach:** And what difference would that make? **Client:** Well, he would be eating better and be more active. **Coach:** OK so 2 things would be different. He would be eating better and he would be more active. Which one do you want to start with first? **Client:** I guess eating better. **Coach:** Ok. So suppose your son was eating better, what difference would that make? **Client:** He would have more energy.	• The client generates their own vision of what they want to be different in the future, based on their own values, priorities and life. • It supports the client to envision a time when things are better and increases their ability to see that positive change is possible.

Sharing resources

Resource

Watch this! A series of simulations have been developed to highlight communication practices when discussing weight management in a spina bifida clinical context.

As you watch the simulation videos, think of these questions:

1. How do you think each of the individuals felt in the situation? Why do you think they felt like that?
2. How successful was the approach used by the healthcare professional? Why?
3. What could have been done differently?
4. What strengths did the family have?
5. What are the main messages you will take away from this scenario?

*For pragmatic reasons, three of the four videos do not show children participating in the conversation. This does not necessarily reflect best practices. Please see the section on 'Who should participate in weight-related discussions?'.

Simulation scenario	Objectives	Brief
Andrew's parents meet with the physiotherapist at their annual appointment at the spina bifida clinic (CLICK HERE TO WATCH THIS VIDEO)	• Discuss the benefits of healthy lifestyles and how they impact participation in life. • Demonstrate how to elicit family/client priorities around healthy lifestyles.	Andrew is an 11 year old boy with spina bifida. His weight has been steeply increasing and he has been finding it difficult to walk long distances. The physiotherapist wants to talk to Andrew's parents about how weight loss and more physical activity could help Andrew maintain his independence.
Amanda's mother meets with a nurse at their annual appointment at the spina bifida clinic (CLICK HERE TO WATCH THIS VIDEO)	• Engage in weight-related discussions with the family while demonstrating dignity and respect.	Amanda is a 7-year old girl with spina bifida. Her mother, Mary, has always struggled with her weight. Discussing weight is difficult for Mary, as she does not want Amanda to feel badly about her body.
Danielle and her mother meet with an occupational therapist at their annual appointment at the spina bifida clinic (CLICK HERE TO WATCH THIS VIDEO)	• Collaborate with the family around healthy lifestyle strategies in everyday living situations.	Danielle is a 14-year old girl with spina bifida, who uses a walker to get around. She enjoys coming home after school and playing video games until she goes to bed. Danielle's mother, Diane, has many stressors in her life.
Salma's father meets with a paediatrician at their annual appointment at the spina bifida clinic (CLICK HERE TO WATCH THIS VIDEO)	• Demonstrate the use of a growth chart to facilitate information-sharing about weight trajectories.	Salma is an 11-year old girl with spina bifida. A recent assessment shows that her body weight has sharply increased. Salma's father is meeting with the paediatrician.

Showcasing evidence: Children with disabilities

Children with Disabilities

Children with disabilities live in the same environment that has led to increased levels of obesity in typically developing children.[48] There are also a number of other factors that further increase the chances of children with disabilities developing higher weights.[49] These can include things such as mobility impairments, medication and sensory issues.[50, 51]

Children with disabilities experience the same physical consequences associated with childhood obesity as typically developing children, but these can be intensified and result in conditions such as pressure ulcers, muscle loss, pain and further mobility limitations. These changes in turn can affect everyday functioning, independence and quality of life. [52, 53]

This section of the Casebook builds on the general principles detailed previously and highlights some of the physical, psychosocial and cognitive issues many children with disabilities experience that add a layer of complexity to discussions about weight. To do this, we have used two examples: a life-long physical disability (spina bifida) and a neurodevelopmental disability (autism spectrum disorder).

Spina Bifida

What is it?

Spina bifida is a neural tube defect affecting approximately 1 in 1000 live births in North America.[54] It affects the spine and can damage the spinal cord and nerves. Depending upon the level of spinal damage, children with spina bifida may walk unaided or with support, and/or may use a wheelchair. Spina bifida is now a non-progressive, life-long condition,[55] making long-term health a particularly important part of clinical care. Obesity is approximately twice as common in young people with spina bifida compared with typically developing peers.[5,6]

Considerations for weight management in spina bifida

- Children with spina bifida have less calorie burning tissue (lean body mass) and a lower rate of burning calories (metabolic rate).[56, 57]
- Children with spina bifida may experience a number of challenges to engaging in healthy lifestyles, including restricted mobility, cognitive impairments (making planning and multitasking difficult) and concerns about incontinence.[56, 58]
- Chiari brain malformation is common and can cause problems with swallowing and gagging, as well as limiting food intake to specific tastes or textures (e.g. simple carbohydrates such as white bread and pasta).
- Children with spina bifida often experience issues with urinary and/or fecal continence, which can be embarrassing and intrude on everyday life. Maintaining bowel and bladder function may therefore be more of a priority to a child than overall nutritional status.[59]
- BMI is not an accurate measure in people with spina bifida[22] and no normative data are available.

> *It needs to be discussed but maybe the professionals, the doctors and also whoever is involved has to really recognize that no parent wants his or her child [with spina bifida] to gain weight. So they have to have that in the back of their mind when they're talking to parents.*
>
> – Father of a 10 year old child with spina bifida

Sharing impact stories

Impact Story

As a physiotherapist working in the spina bifida clinic at Holland Bloorview Kids Rehabilitation Hospital, weight is a topic that Kelly Brewer has discussed with children and their families. Kelly often brings up the topic as part of her clinical assessment, with a lens towards exercise and the benefits of living an active lifestyle; not how much the child weighs or goals to lose weight:

KELLY

"I approach weight around the importance of everyone keeping active and watching their weight… It is important for everyone to try to keep their weight healthy. I also discuss it in relation to the fact that if they are too heavy, their walking may become more tiring (if they are able to walk) or their transfers (if they are a full time wheelchair user) may be more challenging, because the heavier you are, the more weight your weaker muscles have to carry around and lift. The effect on function often resonates with them."

As a physiotherapist within a large multi-disciplinary team, Kelly's particular interactions are largely based on physical aspects of the child's condition or disability. In her experiences, children and their families are receptive to talking about healthy lifestyles, including opportunities for physical activity and recreation.

But there have been times when the conversation has been challenging:

"I have had a few conversations when the parents indicate that they don't have the financial means to take their child to recreational activities. This is always the hardest time for me, as I don't really know what to say. Finding resources to allow you [to go] to a gym is next to impossible, so in those situations, I feel very uncomfortable."

While these topics can be difficult to address, Kelly says that *"hopefully you open the door for families to have these conversations. Weight gain is hard to discuss and knowing that your function could be affected as you age if you continue to gain weight is hard for everyone."*

Impact Story

Meet Isabelle & Geoffrey

Isabelle is an amazing 15 year old girl who is a bit of a mystery … she has an undiagnosed condition. Communication can sometimes be challenging, as Isabelle is non-verbal, severely deaf and developmentally delayed. BUT Isabelle's challenges don't stop her from living life to the fullest and maintaining a social, interactive and healthy lifestyle. Dancing, swimming, arts and crafts, among other activities, play an important role in her health and well-being.

While great efforts are being taken to ensure Isabelle is happy and healthy, an area of particular focus right now for Isabelle's father, Geoffrey, is her weight. Conversations around Isabelle's weight have been raised by a doctor she sees in a nutrition outpatient clinic. Working with the dietitian to find ways to include more vegetables and fibre in Isabelle's diet have been extremely helpful. But for Geoffrey, Isabelle's weight is still a concern:

"[Her] height is not going up as much as her weight. I am not sure what to change in her diet other than to reduce the quantity, but she is always hungry… but I do not want to starve her. It is such a delicate balance being a teenager, not being as mobile as other teens and being just as hungry."

"My daughter is the most important part of my life and I will always do my best for her and cannot do more than my best. I want to keep her happy and to enjoy life as best she can and I will try to keep her height to weight ratio the best ratio I can without getting so stressed as to be sick myself with worry."
- Geoffrey Feldman

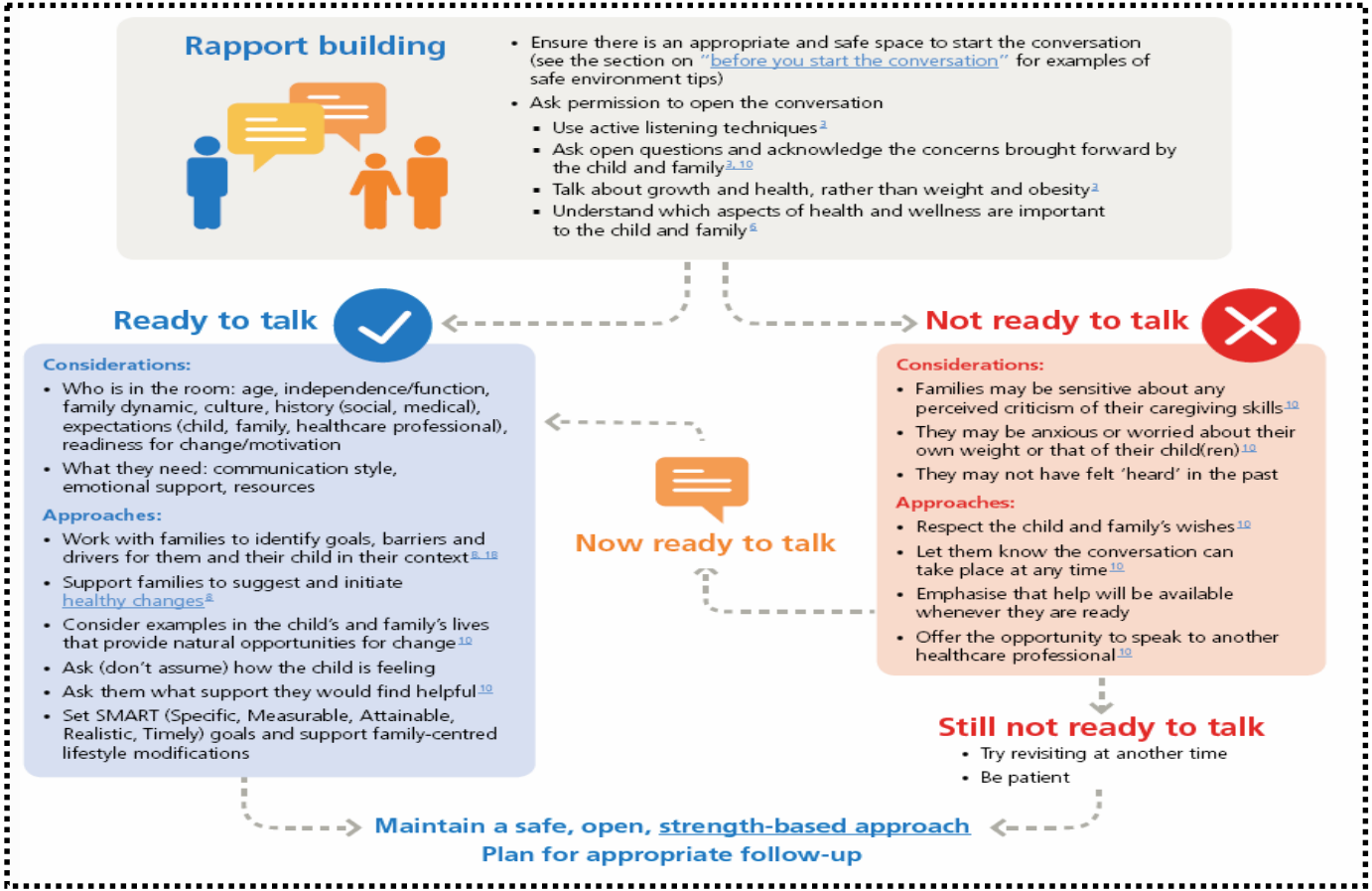
ISABELLE & GEOFFREY

As a parent of a child with a developmental disability, Geoffrey does his best to listen to healthcare professionals and to follow their instructions, but also recognizes that the challenges are immense. For him, sharing his stresses and challenges in following instructions is all part of the weight-related conversation.

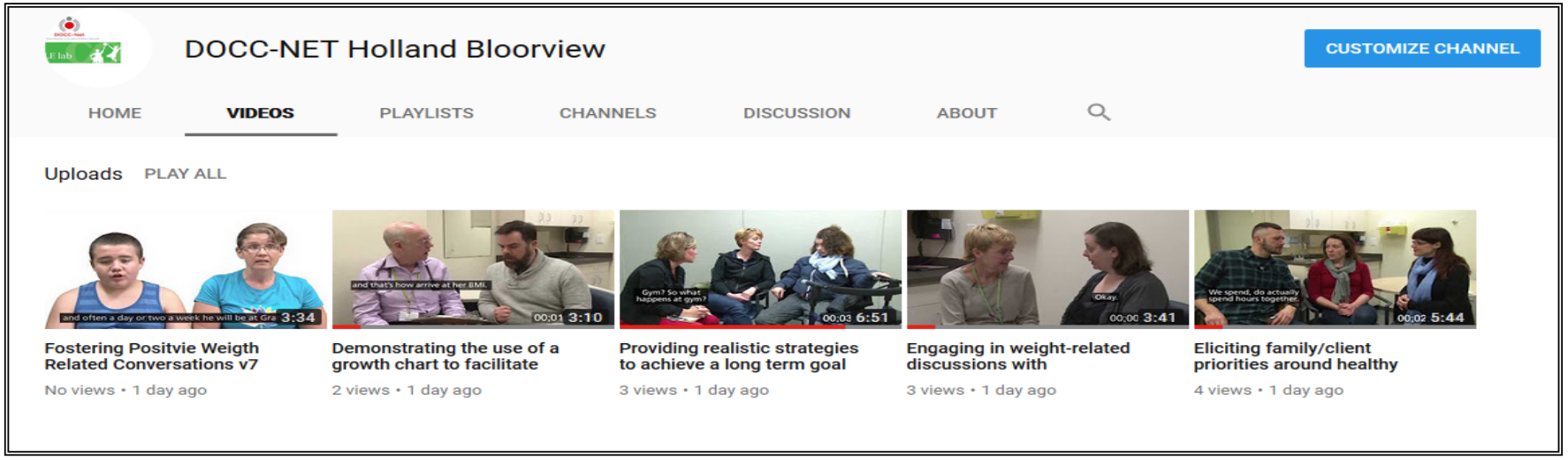
His advice to healthcare professionals is to *"keep up the conversation, but to also realize the pressures of the primary family trying hard to maintain a proper balance of food intake vs outtake, height vs weight, health vs sickness, exercise vs mobility, and…daily medications."*

Thank you Isabelle & Geoffrey.

Sharing resources: Pathways



Sharing resources: DOCC-NET Youtube Chanel



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ProFILE lab

Accessing the Casebook

Home > Research Centres & Labs > ProFILE Lab > Knowledge Translation Products

Knowledge translation products

Providing our clients with the best possible care is a priority at Holland Bloorview. Using timely research evidence, combined with clinical expertise, is important in creating resources to help with the promotion of health and well-being of children with disabilities and long term conditions.

Both promoting healthy lifestyles and discussing weight-related topics are priority areas of investigation by the ProFILE lab, and so we are developing a suite of evidence-based products to help address gaps in this area.

To access our products, please click on the links below:

Weight-related Conversations
Knowledge Translation Casebook

Learn more

- Mission
- Our people
- Research
- Publications
- **Knowledge Translation Products**
  - Knowledge Translation Casebook
- Lab Highlights
- DOCC-Net

Freely available for download at:
www.hollandbloorview.ca/ConversationCasebook

Accessing the Casebook

Weight-related Conversations
Knowledge Translation Casebook

Having conversations about healthy lifestyles and wellness as they relate to weight-management can be challenging for children, their families and healthcare professionals. Healthcare professionals are expected to be proficient in effective communicating about such topics, however, many report wanting more support.

The ProFILE lab with support from Evidence to Care, have developed a practical, evidence-based resource to support healthcare professionals to have positive conversations about healthy lifestyles and weight-management with children and their families. The PDF document is available for free download by clicking on the link and/or image below.

Please tell us about yourself. By providing the following information, you will help us better understand who is using the Knowledge Translation Casebook and where the Casebook is being used.

Email:

Role:

Organization:

Submit

Holland Bloorview Kids Rehabilitation Hospital

Weight-related Conversations Knowledge Translation Casebook (PDF)

This Casebook is a compilation of best evidence and practice to assist healthcare professionals in having positive conversations about weight-related issues with children and their families.

Learn more

- Mission
- Our people
- Research
- Publications
- Knowledge Translation Products
- **Knowledge Translation Casebook**
- Lab Highlights
- DOCC-Net

Freely available for download at:
www.hollandbloorview.ca/ConversationCasebook

But…

How can it be used in practice?

Guiding the conversations: 5 key questions

Which of the 5 questions do you feel you tackle well? How do you do that?

Which questions have you had challenges with?

Activity: In pairs/ small groups:

- Share your successes: how did you accomplish them?
- Identify questions you have experienced challenges with
  - *Discuss which of the resources/ techniques you heard about today could help with those challenges*
- Identify one thing you will do differently in your practice after today's workshop

Acknowledgements

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Student Facilitators: Emily Rowland, Meaghan Walker, Celia Cassiani, and Patrick Jachyra

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Questions?