Lifelong Smiles for People with Intellectual Disabilities:
A Resource for Oral Health Professionals

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Today...

- Getting the facts:
  - How does Canada measure up to other countries
  - The BC experience for individuals with ID
- Special Olympics BC & the Healthy Communities Initiative
- Lifelong Smiles resource development
- Components, objectives, evaluation
- Next steps
Getting the Facts
Canadians with Intellectual Disabilities
Obesity is a major issue

Weight - Adults
Source: Special Olympics Healthy Athletes screenings 2007-2016

Graph showing obesity rates in different regions:
- Global
- North American
- Canada
- British Columbia

Overweight and Obese categories are indicated by different colors.
Obesity is a major issue

Weight - Youth & Adults in B.C.
Source: Special Olympics Healthy Athletes screenings 2007-2016
Live Healthier ~ Hearing

Source: Special Olympics Healthy Athletes screenings 2007-2016
Special Olympics BC Findings
Healthy Athletes Survey

- 7.5% of athletes do not have a full-time physician based in their community
- 32.25% of athletes need to travel outside of their community for medical services ‘some or most of the time’
- 50% visit a medical professional more than four times per year
- 12.5% visit 10+ times per year
- 92.6% said that they would like to get in better shape
- 20% stated that poor health had at times prevented them from competing in sports
- 12.5% have been unable to purchase necessary medications due to insufficient funds
- 20% are unable to purchase their required sports related medical devices in the community
- 57.6% of caregivers have less than four years’ experience working with people with ID
80% of athletes at least sometimes find it difficult to understand their doctor’s advice or directions, yet only 31% always have somebody to accompany them to their doctors’ appointments.

Source: Special Olympics BC Healthy Athletes Survey
93% of undergraduate medical students in Ontario thought they should have more training on treating people with intellectual disabilities.
Live Healthier ~ Dental

Source: Special Olympics Healthy Athletes screenings 2007-2016
Special Olympics BC’s Action Plan is about...

- Engaging the healthcare community through universities/colleges, licensing bodies,…
- Growing Healthy Communities programs
- Developing a strategy to improve follow-up care after screenings
- Engaging athletes in health training
- Educating government
- Increasing awareness and education for healthcare providers to support families/caregivers/athletes toward a healthy lifestyle
Healthy Communities

Launched as recognition program in 2015 to:

- Strengthen Healthy Athletes as the foundation of SO health program
- Link athletes to follow up care, health services and resources
- Link athletes to ongoing health and wellness opportunities
- Weave health throughout all Special Olympics programming
- Build awareness
- Contribute towards creating a tipping point for inclusive health for all

British Columbia received 1st grant in Canada for sustainable health initiatives
Lifelong Smiles: Guiding Principles for this project...

- Vision:
  - Increase access to dental care for individuals with ID

- Goal:
  - Enhance oral health professional’s knowledge, awareness, and abilities to provide dental care to those with ID

- Approach:
  - Evidence-informed, real-life scenarios and reflections, build on existing resources

- 6 month project timeline
Creating the resource, 1 step at a time...

1. Review existing literature and resources, prepare list and circulate

2. “Meeting of the Minds” ½ day engagement session
   - 30 individuals from BCDA, BCDHA, CDHA, educators, clinicians (DDS, RDHs), public health
   - Reviewed resources, identified gaps, brainstormed topics
   - Follow up and feedback received to reach consensus on 4 priority topics

3. Oral Health Resource Development full day session
   - Team of 6 educators with experience with public health and ID
   - Product: Framework for content development of 4 modules

4. Course/module outlines, slide content, speakers notes, references/resources, tools:
   - 6 writers, SOBC

5. Content circulated for review/feedback to SOI Drs. Perlman & Wong, oral health professionals
Creating the resource, 1 step at a time...

6. Photo shoot & videotaping: Vancouver Children’s Hospital Dental Clinic

7. Videotaping speaker

8. Merging all products into one

9. Review again and again ~ final product

10. Landing page creation, recognitions, resources, evaluation components (quiz, feedback)
Lifelong Smiles for Individuals with ID: 5 Essential Steps for Oral Health Professionals

1. Supportive legislation, policies and programs
2. Knowledgeable, willing oral health professionals
3. Supportive dental team and clinical environment
4. Strategies in place to shape desired behaviour
5. Upstream client-centred approach for daily oral care
Learning Objectives:

1. Define and describe intellectual disability, its prevalence and etiology, associated health disparities and access to care barriers experienced by this population

2. Identify current supportive legislation and programs

3. Recognize the importance of advocating for individuals with ID

4. Discuss a step by step approach to prepare the dental team, client, family members/caregivers, and clinic environment to successfully welcome clients with ID

5. Identify effective behavior modification theories, strategies and tips that can help shape desired behavior and increase success during dental visits

6. Employ an upstream, client-and caregiver-centered approach to support effective daily oral hygiene for clients with ID
Life Long Smiles for Individuals with ID

- Open Source ~ FREE access to anyone
- Resources posted on the Canadian Dental Hygienists Association website under “online courses”
- 4 modules ~ each with separate References/Additional Resources list; several additional tools provided
- What is most unique?
  - Captured reflections, stories, feedback from individuals with ID, parents, caregivers, oral health professionals
Lifelong Smiles for People with Intellectual Disabilities

Course Description:
Individuals with intellectual disabilities (ID) often experience challenges in daily oral hygiene, have more untreated dental caries, and have a higher prevalence of gingivitis and other periodontal diseases than the general population, all of which can affect their oral function, overall health, quality of life, and longevity. These individuals commonly face significant access-to-care barriers and challenges in receiving dental care.

The Lifelong Smiles for Individuals with Intellectual Disabilities online course is designed to help you, the oral health professional, more effectively connect with and support clients with ID in maintaining good oral health over their lifetime. This four-module course, developed by dental hygienists, is made possible through a partnership with Special Olympics BC and the Gulsano Foundation’s Healthy Communities program.

The four modules are:
- Facts about individuals with intellectual disabilities
- Preparing the dental office to welcome clients with intellectual disabilities
- Desensitizing strategies for a successful dental appointment for individuals with an intellectual disability
- Strategies to support your client’s daily oral care

Course Details:
- Join CDHA Today
  - Incredible pricing on our courses is just one of the many benefits of CDHA membership. Join CDHA Today!

Pricing:
- CDHA member fee: FREE
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- Non-member fee: FREE

Note that your access to this course will expire one year from the date of registration.

http://www.cdha.ca/cdha/Education/Online_Courses/

- Search for “CDHA online course”
- Register
- Access Your Account
- Click on link and begin learning
### Lifelong Smiles Online Resource is self-paced...

<table>
<thead>
<tr>
<th>Module</th>
<th>Title</th>
<th>Estimated time needed to complete</th>
<th>Evaluation 80% pass rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Learning more about Individuals with ID</td>
<td>42 minutes</td>
<td>✔</td>
</tr>
<tr>
<td>2</td>
<td>Preparing the dental office to welcome individuals with intellectual disabilities</td>
<td>40 minutes</td>
<td>✔</td>
</tr>
<tr>
<td>3</td>
<td>Desensitizing strategies for a successful dental appointment for individuals with intellectual disabilities</td>
<td>43 minutes</td>
<td>✔</td>
</tr>
<tr>
<td>4</td>
<td>Strategies to support your client’s daily oral care</td>
<td>32 minutes</td>
<td>✔</td>
</tr>
</tbody>
</table>
References, current resources, tools...

References:

- Howe, J. (2016). No one. BC framework for the development of a service framework for people with an additional health concern. For People with

Additional Resources:

- FireShot Screen Capture #
- FireShot Screen Capture #
- FireShot Screen Capture #
- FireShot Screen Capture #
- FireShot Screen Capture #
Module 1: Getting the Facts on Individuals with ID
0.4 - 1.2% of Canadians have an ID (55,000 - 510,00 potential Canadian dental clients) (Statistics Canada, 2012)

- Etiology for 30-40% of clients with ID is unknown

- Known etiologies include genetic disorders & pregnancy complications

- Increasing lifespan resulting in more middle-aged and elderly patients with ID (Lin, et al., 2014)
Autism Spectrum Disorder: Early Signs

- Does not respond to his/her name by 12 months of age
- Doesn't follow directions
- Seems to hear sometimes, but not other times
- Doesn't point or wave "bye-bye"
- Doesn't smile when smiled at
- Has poor eye contact
- Seems to tune people out
- Spends a lot of time lining things up a certain order

- (Special Olympics, 2017)
Oral Conditions Associated with Down syndrome

- Delayed and altered sequence of eruption
- Delayed exfoliation
- Microdontia and/or missing teeth
- Shorter roots
- Small oral cavity, macroglossia
- Underdeveloped maxilla leading to malocclusion
- Narrow palate
- Higher incidence of enamel hypoplasia
- Increased risk of periodontal disease (leukocyte impairment)

(Chin, et al., 2017)
Advocacy

- Write submissions and lobby government to make changes that promote and protect the rights of people with disability
- Help clients by educating caregivers on the relationship between preventive care and systemic health
- Share your positive experiences with peers
What Caregivers & Family Want You to Know...

- Can be an invaluable source of information and support
- Can assist before, during, and after dental visits
- Emphasize the importance of involving and communicating directly with the client with ID, then if needed with the caregiver
- Are interested in helping to reduce risk of oral health problems
  - Ask you to be realistic with expectations and suggestions for daily oral care and their dental treatment plan

Mom assists during appointment
Reflection from Judy, a caregiver
“Most attitudes toward people with intellectual disabilities are framed by negative stereotypes and misconceptions. Yet when people see Special Olympics athletes in competition, they find their attitudes changing not just about what those with intellectual disabilities can do, but also about what they themselves can do to help build a better world.”

Special Olympics British Columbia
Ken reflects on his experiences with Special Olympics and Special Smiles
Module 2: Learning Outcomes
Preparing the dental office to welcome clients with ID

- Highlight current legislation in BC that mandates program development for individuals with ID
- Explain the concept of informed consent & its importance in oral healthcare
- Discuss the importance of a team approach to oral healthcare for individuals with ID
- Identify practical tips for preparing the dental office to welcome individuals with ID
- List strategies and tips to support effective communication with individuals with ID and their family members
- Select strategies and tips to use for the “meet and greet” as well as subsequent appointments
- Identify strategies in care plan design for individuals with ID
Informed Consent

What is Informed Consent?
- Making an intelligent decision based on full disclosure of facts
- An explanation of risks, benefits and alternatives
- Health Care (Consent) and Care Facility (Admissions) Act

Why is informed consent important when seeking oral healthcare particularly with respect to individuals with ID?
- Capacity to consent to treatment must be assessed
- Legal implications for oral healthcare professionals
Team Approach to Dental Care

- Requires all team members to be on board in order to provide care in the dental office for individuals with intellectual disabilities
- Each member will have a unique role
- It starts at first point of contact and continues through initial and then subsequent appointments
The dental office welcome package should include:

- A description of what to expect on the first “meet and greet” visit
- A Health history form to complete
- Dental games and recommendations on necessary supplies
- Suggestions on how to create a social story
- Photographs of staff and the office
- A list of steps that will take place during the first few visits
Preparing the Dental Office

- Schedule your client’s visit when office is quieter
- Keep things clean and remove anything that might be frightening
- Avoid strong scents/smells
- Minimize flickering lights for those who are visually sensitive
- Avoid loud noises during the appointment
- Provide pictures of the dental team for the family/caregiver
- Provide pictures of the dental operatory/office waiting room
- Have a sensory box available for the client to explore

Example of sensory box items
Augmentative and alternative communication (AAC)

- All forms of communication other than speech used to express thoughts, needs, ideas and wants (Beukelman & Mirenda, 2013)
- May be aided or unaided
- Impact of the use of AAC in communication (Cannellla-Malone et al., 2009)
Tips for Effective Communication

- Be patient
- Use simpler language, slow the pace when speaking, use a variety of methods of communication
- Describe procedures in steps; first determine how many commands a client can follow
- Treat individuals with ID as peers and do not speak down to them
- Ask questions and allow the client to respond
- Expect a lot of questions so allow ample time to answer
- Include parents/caregivers when appropriate

Do2Learn (n.d.), PBS Parents (2012)
Video Clip Module 2
What to Expect in Module 3

- How to manage and support success at a dental appointment for a client with an Intellectual Disabilities (ID)
- Strategies and tools for modifying behaviour
- Desensitization strategies for clients with ID
Module 3: Learning Outcomes

Desensitization strategies for a successful dental appointment

- Identify strategies to increase cooperation of clients with Intellectual Disabilities (ID)
- Define the “ABCs” of behaviour modification model and discuss why it contributes to successful management for clients with ID
- Discuss strategies to motivate and encourage cooperation during dental appointments for clients with ID
- Describe the “discrete trial method” of pre-planning
- Utilize a visual schedule when providing dental care for individuals with ID
Behaviour Management

- Applied Behaviour Analysis (ABA)
  - Evidence-based theory
  - Focuses on analysis and modification of human behaviour
  - Addresses environment to achieve desired behaviour
  - Key is to prevent difficult behaviour from occurring
  - Recognizes that challenging behaviour is responsive

(Autism Speaks Autism Treatment Network, 2012)
Behaviour Management Models Based on ABA

- Positive Behaviour Support (PBS)
- D-Termined Program of Repetitive Tasking and Familiarization in Dentistry (Alhumaid et al., 2016)
Positive Behaviour Support/Strategy

- Offers positive behaviour support - not control (Autism Speaks Autism Treatment Network, 2012)
- Seeks the cause for the behaviour rather than assigning blame
- Recognizes the individual’s unique strengths and talents
- Upholds respect, quality of life, effective services

Video: Strategies for Effective Behavioral Intervention (Foster, 2015)
https://www.youtube.com/watch?v=iRJRJllosSw
Desensitizing Strategies

- Social Stories
- Modeling
- Role Playing
- Voice Control
- Communication
- Distraction
- Sensory Techniques
- Scheduling
- Discrete Trial Learning
- Visual Schedules/Token Boards
Louise and her son Jack
Module 4 Learning Outcomes

Strategies to support your client’s daily oral care

- Assess the daily oral care needs for a client with an intellectual disability (ID)
- Develop a daily oral care plan for a client with an ID
- Promote effective oral care by engaging clients and caregivers with information, demonstration, and hands-on practice to support daily oral care
- Discuss strategies with caregivers to help support success during daily oral care at home
- Prepare a daily oral care plan for an individual with an ID
Summary of Module 3

- Theories to help shape desired behaviour
- Strategies to motivate and encourage cooperation
- Strategies and tips to increase success when providing dental care
Daily Oral Care Plan: Important Factors to Consider

Your client’s:
1. intellectual and functional abilities
2. Current oral-self care practices
3. Oral health knowledge
4. Home environment
5. Daily oral care needs
Oral Care Products

- Tool/strategy dependent on individual’s abilities and dexterity
- Both manual and mechanical plaque removal options

Tools and strategies for Interdental cleaning
Tips for Sharing Oral Care Information with your Client

- Emphasize the importance of effective daily oral care
- Allow time to adjust, learn and become comfortable
- Include choices – provide client with some control such as colour of toothbrush
- Use caring, clear, active listening
- Provide simple, concrete directions
- Demonstrate instructions and have client demonstrate these to you
A Visual Reminder is an excellent tool to support daily oral care for an individual with an intellectual disability.
Next Steps...

- Officially online June 27!
- Communication strategy
- Target dental/dental hygiene associations, regulatory bodies, educational programs
  - SOBC communities, partners, collaborators, allied health professionals
- Metrics ~ quarterly stats
  - No. of participants, designation, location of practice, quiz results
  - Target goal: 200, hoping for much much more!
- Participant feedback:
  - Content, speaker, knowledge acquisition, readiness to provide care, potential barriers

*Healthier Lifelong Smiles for Individuals with Intellectual Disabilities*
Ken reflects on his experiences with Special Olympics and Special Smiles