Part of working with people who have intellectual and developmental disabilities (IDD) means supporting them through challenges, big and small, including the sometimes uncomfortable necessities of daily living. One example of this is helping with maintaining good oral hygiene and visiting the dentist. People with IDD may not brush their teeth regularly and, even if they do, it can be hard to do a good job. Some of the medications they take (like seizure medications) can harm their teeth. Not going to the dentist often enough can make things worse.

Let's be honest: Dental procedures can be anxiety provoking for anyone, no matter how prepared you are. Adults with IDD may experience a lot of anxiety around dental procedures, which often means that the dentist is not able to do a thorough job. This can result in multiple appointments in order to have the issue resolved, possibly leading to additional discomfort and pain. Importantly, some adults with IDD may show this pain and discomfort through behaviours. Because of these challenges, procedures can also be rushed, either by the patient or the dentist. This too can delay the time it takes to identify that this person is experiencing pain, and where it may be coming from. Pain may increase anxiety and behaviours due to the agony the individual is going through. This can be especially difficult when a person with IDD does not communicate traditionally and may not be able to express how they are feeling.

In an effort to help with these challenges, we have put together some helpful hints and strategies from direct support professionals and dentists to help with identifying dental health issues, improving oral hygiene, preparing for dentist appointments and making them more successful.
Tips from Dentists:

Dr. Alison Sigal
Dr. Michael Sigal

Teeth cleaning will be shorter if teeth are cleaner to start with. Here are some things you can do at home to help with oral hygiene.

Helpful Reminders Regarding Oral Hygiene Care:

1. If the lips are hyperactive/hypertonic (i.e., very tight and strong), gently pull back (retract) the lips so you can see the gingival (gum) area. “You can't clean it, if you can't see it.” If this is not done, you are most likely only brushing the occlusal/biting surface of the teeth.

2. If the person you are supporting is not able to brush well on their own, then someone else must supervise and help them with it. With the person seated or standing, you could try standing behind them when brushing their teeth; in this way, you can mimic the sweeping motion you do in your own mouth, transferring the same motion to them. From this position, you should have a clear view of all the teeth (unobstructed view of the oral cavity and all the teeth).

3. For people who are prone to gum disease, rinsing with a mouthwash may help. First you have to make sure that they can both rinse and spit. If they cannot, a small amount of oral rinse products can be applied to the teeth and gums with a toothbrush.

4. If co-operation permits, flossing between teeth is ideal. A floss wand or longer handle flosser can work great! Avoid putting your fingers between anyone’s teeth, as this increases the likelihood of being bitten.

5. If a patient has trouble with opening their mouth, you can help clean their teeth by brushing the outside (buccal/cheek) surfaces of the teeth which doesn’t need them to open their mouth or keep it open. The tongue should self-cleanse the inside (lingual) surfaces of the teeth.

6. Often family/care workers won’t brush the teeth as they are afraid that they might get bitten. If you keep your fingers between their cheeks and not between their teeth – you will not be bitten. See point 5 as a helpful tip.

7. Keep on brushing. Don’t give up, and remember that you are trying to teach them acceptance of this important daily oral health practice. Show them how it is done. Watch videos and practice.

8. If the tongue is coated with debris – brush it too!

Image from: https://www.which.co.uk/reviews/electric-toothbrushes/article/how-to-brush-with-an-electric-toothbrush
9. Sometimes we hear from staff that, even though cleanings are okay at the dentist’s, it is hard
to do at home. This could be because the teeth and gum brushing is too aggressive, which
can be quite uncomfortable and even cause some pain. **Remember the mantra - to be**
**Gentle but Thorough!** As a starting point, it is better to have a routine of brushing, even if it
isn’t perfect, than not to do it at all, then gradually make it a little longer and more thorough.

10. These are just guidelines, and need to be modified for each person. Remember to work with
your dentist, who is there to help you learn how to provide the best oral care to the person
you are supporting to the best of your ability.

**10 Signs of Possible Dental Health Problems**

As a direct support professional, you have the ability to help make sure that the people you
support have good oral health. Do your best to ensure that good daily oral hygiene is
happening. If you aren’t sure how, ask for help at your dentist visit. Practice with the dentist or
hygienist watching, take a video. Get creative but make sure everyone involved knows how to
do it right.

If you notice any of the 10 observations listed below, it may indicate that the person you are
supporting is experiencing pain, and the source (or cause) could be related to their teeth or oral
cavity. If this is happening, you should have them seen by an oral health professional for an
assessment as soon as possible to either confirm or rule out a dental source for the pain.

1. Any changes in their eating and/or drinking? (e.g., avoiding their favourite foods/drinks)

2. Experience sensitivity/discomfort to cold or hot foods?

3. Any changes in their behaviour – more aggressive to themselves or others, more excited or
more withdrawn?

4. Any changes in their sleeping pattern? (e.g., waking up more frequently, waking up in
discomfort)

5. An increase in teeth grinding, clenching, or drooling?

6. Are they recently avoiding daily oral care?

7. Any facial swelling or redness on one side of their face, possibly with a fever?

8. Do they have really bad breath?

9. Have they required more medications such as their PRN medications for pain or behaviour?

10. Ask the person if you can look into their mouth, then LIFT the LIP – Do you see red,
    inflamed gums that bleed on looking or touching with a toothbrush, broken teeth, holes in
teeth, pimples/boils/swellings on the gums?
Tips from Direct Support Professionals:

Sarah Bachle
Arlene Wright

Strategies to use before going to a dental appointment

✓ Encourage the person you are supporting to practice proper oral hygiene to avoid major dental concerns as much as possible. Using a “first and then” process with oral hygiene paired with a preferred activity can be helpful for some.

✓ Develop communication and understanding around oral hygiene, and a way to communicate if the person you are supporting has discomfort or feels changes in their oral health.

✓ Try to schedule appointments with a dentist and dental hygienist with whom they are familiar, and who has an understanding of working with individuals with developmental disabilities.

✓ Have a staff that has developed a trusting relationship with the individual attend the appointment with the person so they feel comfortable and safe.

✓ Take the opportunity to have some one-on-one time before the appointment (e.g., to have a preferred meal, especially if the expectation is that no solid food can be eaten afterwards). Talk about what to expect while at the dentist (note: this may be helpful for some, but not for all – being aware of the person’s needs at this time is important).

✓ Plan to bring a second Direct Support Professional for extra support if needed/possible.

✓ Identify whether the person going to the appointment may need a PRN for anxiety or pain before attending the appointment as a form of relief and/or to help with coping through the appointment.

✓ Deep breathing, muscle relaxation, exercise, and mindfulness activities can help reduce anxiety about the appointment, and doing them along with the person you are supporting can help model and teach these skills.

Strategies to use during the appointment

✓ Ask the person working at the front desk if they can let you know how long it will be until the dentist is ready so that you have the option of leaving and coming back later.

✓ Offer to stay in the examination room with the person you are supporting, and let them know that you are there in case they need reassurance or support.

✓ Using humour to lighten the mood can help, or try to have them focus on an upcoming special event.

✓ Take along a favourite activity or preferred item.

✓ Listening to music and wearing sunglasses can help reduce some of the anxiety that comes from the dental instruments.
✓ Ask the dentist or hygienist if the person you are supporting can take a break if they need to. Even a quick minute to catch their breath and give a high five can help keep the appointment on the right track.

Strategies to use after the appointment is over

✓ Often at the end of the appointment, the dental hygienist will provide a new toothbrush or item. If the person you are supporting looks forward to this, emphasize that they did a good job while giving them this item (positive praise for a job well done should always be a given).

✓ Schedule a preferred activity to look forward to after the appointment. Make sure that this is realistic in order to keep your promise.

✓ If a procedure was performed, and the person being supported is instructed not to eat solid food for a period of time following the procedure, take them to the store either before or after the appointment, so that they can pick out foods that are safe for them to eat (e.g., their favourite soup, juice, etc.).

✓ Monitor for pain after the appointment and, if prescribed, offer pain medication as needed.

✓ Talk to the person about what went well during the appointment, and what might they want to change for next time.

Remember, going to the dentist is often not easy and your empathy and support go a long way in helping to make the experience more positive for the person you are supporting.

Success Story: How Using These Strategies Made for a Better Dentist Appointment

This is the story of a young woman named Jane (whose name has been changed to protect her confidentiality). Jane and the staff working with her implemented many of the strategies and tips mentioned above before, during, and after the appointment to make Jane’s experience at the dentist better. Jane had limited ability to communicate verbally and lived in a residence being supported by an agency in the social services sector.

Jane had an upcoming dentist appointment. She always dreaded going to the dentist. Jane’s appointment was going to be held in a busy city. For Jane, the city was already a scary place and having to look out the window at the hustle and bustle of people and cars, and then taking a ride through the endless maze of parking garages that remind her of the last time she was there, was quite anxiety provoking for her. On top of that, arriving in the waiting room of the dental office, seeing others who are also very nervous about their visit seemed to remind her of the experience that awaited her.

As soon as the staff who worked with Jane booked the appointment, they began working with her to implement some strategies to try to make the visit more bearable for her.
How did they prepare for the appointment?

- The program arranged for a DSP who was familiar to Jane to support her for this appointment. This helped because this was not the first time they had experienced this together, and Jane trusted and felt more comfortable with her support.
- The DSP knew that it is helpful for Jane to announce their arrival to the person working at the front desk, give them her phone number, and ask them to call when the dentist is ready for them. At this time, they could leave the waiting room (which was a stressful environment for Jane) and go downstairs to have a tea while they waited.
- The DSP that was supporting Jane knew that they had been working on dental hygiene at home and hoped that this visit had great results so that Jane would not have to go back for any fillings or further dental work.
- The DSP brought Jane’s PRN medication from home that she uses for anxiety and nervousness, and while they had their tea, (as they knew it would be a while before the dentist was ready for them), she showed the PRN medication to Jane and asked her if she would like to take one to make the appointment less stressful. At this point, Jane recognized her pill that helps her to relax and said, “Yes” she would like one.

Strategies used during the appointment:

- After about half-an-hour, the DSP received a call from the receptionist at the dental office, saying it is Jane’s turn to see the dentist. They both returned to the dental office and went directly into the room, therefore avoiding the waiting room.
- The DSP reviewed some of the strategies with the dentist that have worked in the past to help ease the situation. Some of the strategies they used are: moving the dental instruments out of sight, telling Jane what is happening as the dentist is working, and making sure that the support professional can stay in the room as the dental work is being done. The DSP also explained that it would be helpful for the dentist to work as quickly as possible and to give Jane the option to stop the dental work if it becomes too much for her to handle.
- Jane was able to sit still with her mouth open for about 20 minutes, which was the longest she had ever done in a dentist office, and the dentist gave her positive feedback about her patience and the results of her dental exam.
- Jane received her new tooth brush, which is something that she looks forward to when she visits the dentist. Jane had a good report from the dentist who told her that she has no cavities and can come back in six months for her regular cleaning. This report gave Jane, as well as the DSP encouragement that all the hard work they had been doing at home to improve Jane’s dental hygiene had not gone unnoticed.

What did they do after the appointment?

- Jane and the DSP left the dental office with smiles on their faces and were relieved that the appointment was over and went well. They decided that they would go out for lunch to celebrate a job well done.
- The DSP is also elated that Jane is happy about the appointment and can go home that evening, knowing that the strategies that she used to help support Jane were successful.
- The DSP made sure to go back to the home in which Jane resides and shared this information with the other support professionals as a way of passing on this success story.
Taking these strategies into consideration may help ease the process of going to the dentist and make it more enjoyable for the person you are supporting. However, there will often still be feelings of pain and anxiety for the people we support around going to the dentist. As DSPs, we need to be flexible, patient, empathic and, most of all, take the time to develop a good trusting relationship/rapport with the people we support. Remember, going to the dentist is not easy for anyone. Your pre-planning, support and follow-up support goes a long way!

Resources:

Resources for DSPs:
- Little Bird Dentistry: www.littlebirddental.ca
- Oral Health Total Health website: www.ohth.ca
- National Institutes of Health Dental Care Guidelines: https://www.nidcr.nih.gov/health-info/developmental-disabilities
- News article highlighting some of the issues around dental care for adults with developmental disabilities: https://www.bbc.com/news/uk-england-hereford-worcester-46522258

Leaflets for Adults with IDD: http://www.easyhealth.org.uk/listing/teeth-(leaflets)

About the Authors

Arlene Wright has been working as a Direct Care Worker since 2002 with Vita Community Living Services. She has the privilege of supporting individuals in managing their day-to-day needs within the community and at home. Arlene is a graduate of the Social Service Worker Program at Seneca College, the Child Youth Worker Program at Centennial College, and the Rehabilitation Service Worker Program at Seneca@York University.

Sarah Bachle graduated from George Brown College in 2004 as a Human Services Counsellor with a focus on mental health, addictions, and criminal justice. She has been working as a direct support professional for 14 years in mental health and dual diagnosis. Over the past two-and-a-half years, she has been working as a supervisor for residential programs and has had the great opportunity to be a part of the Nuts and Bolts for Health Care project, bridging the gaps between the social service and health care sectors in Ontario.

Dr. Alison Sigal graduated from McMaster University with an Honours degree in Kinesiology before attending the University of Toronto, Faculty of Dentistry where she earned her Doctor of Dental Surgery and Masters of Science Degree with Specialty training in Pediatric Dentistry. She is currently practicing in Milton, ON at Little Bird Pediatric Dentistry, which she opened in 2017 to provide comprehensive oral care to all children from birth onwards, and persons with special needs of all ages. In 2008, she founded the Federal Non-Profit Organization, Oral Health, Total Health (OHTH; www.ohth.ca) dedicated to advocating, educating, and improving access to oral health care for persons with special needs. She is also the primary dental consultant to Special Olympics Ontario – “Healthy Smiles” initiative.

Dr. Sigal is a retired Professor of Pediatric Dentistry at the Faculty of Dentistry, University of Toronto where he was the Director of the MSc Graduate Specialty Program in Pediatric Dentistry for more than 20 years. He was also the Dentist-in-Chief and Co-director of the Mount
Sinai Hospital Dental Residency Program for 15 years. A graduate of the Faculty of Dentistry University of Toronto (DDS 79, Internship 80, Diploma Pedodontics 82, MSc 84), he has devoted his academic and clinical career over the past three decades to improving and providing dental care to children of all ages especially those that are underprivileged, and to persons with special needs or disabilities of all ages. He has now joined Dr. Alison Sigal at Little Bird Pediatric Dentistry to provide community based care to children and persons with special needs in a clinic designed around the behavioural needs of children and persons with disabilities.

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Heather Hermans has worked for over 25 years with people with Intellectual Disabilities. Heather has led numerous teams in supporting people with a variety of needs to transition from institutional settings into community and treatment settings. A Developmental Service Worker graduate with a post-graduate certificate in Teaching and Training Adults, she continues her education as a student of the Disabilities Studies Undergraduate Program at Ryerson University in Toronto.

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