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This page is part of a period education guide, a collection of resources designed to support menstruation. See the rest of the guide here: <u>Period Education Guide</u>

About this Guide:

The purpose of this guide is to provide quick reference resources related to periods and menstrual hygiene management for all people. Healthcare providers, educators, caregivers, and young people are encouraged to use this guide to learn about menstruation.

Background:

According to the United Nations Children's Fund (UNICEF), 1.8 billion individuals worldwide have periods and thus, are expected to engage in menstrual hygiene management (MHM). The World Health Organization (WHO) and UNICEF define MHM as: "the management of hygiene associated with the menstrual process" (1, p. 16). WHO and UNICEF break down the activity into three subactivities; using and changing bloodabsorbing products, washing the body, and disposing of used menstrual products (1).

A literature review on MHM for youth who experience intellectual and developmental disabilities (I/DD) revealed that the above definitions and descriptions fall short of encompassing the multifaceted and complex nature of menstruation and MHM. The review of the literature included qualitative and quantitative data gathered from healthcare providers as well as people with disabilities and their families. It included the following themes:

- assistance from family/caregivers
- seeking and receiving information about menstruation and MHM
- skills training interventions to improve performance and independence in MHM

Background (continued):

Notably, this topic and all of the aforementioned themes are significantly influenced by the socio-cultural context in which they occur. Wilbur et al., (2) proposed that MHM is not commonly studied due to the taboos and stigmas around menstruation. Further, the intersectionality of disability status and menstruation exacerbates concerns about stigma, reduces research on the topic, and hinders healthy and equitable engagement in MHM. At this time, there is no research within the occupational therapy (OT) literature that explores or describes MHM programs for youth with I/DD. Correspondingly, although Gray et al., (3) found that parents of children who experience disability desire anticipatory guidance in regard to puberty and periods, in a nonexperimental survey study designed to identify OT practice trends for addressing puberty, Larson et al., (4) found that few occupational therapy practitioners (<26%) addressed menstruation in clinical practice.

Steward et al., (5) concluded a need to improve the accessibility of detailed and specific menstruation-related knowledge to support menstruating individuals. This was the first study conducted that included Autistic participants' perspectives on menarche and menstruation. The study found that participants across both groups reported support needs in the areas of:

- learning about periods as a natural bodily function
- learning how periods can affect them
- learning what is considered normal or not normal during their menstrual cycle

Additionally, Autistic participants reported that periods exacerbated their Autism-related challenges and that they were less likely to learn about periods from friends than their non-Autistic peers (5).

Background (continued):

The above findings align with overall gaps in supports related to the broader topics of puberty and sexual education for youth with I/DD. People with I/DD have historically been excluded from these topics, but all individuals have the right to learn about and make decisions about their own bodies. As such, this capstone aims to bridge the gaps in MHM supports to improve the health and quality of life for menstruators who experience I/DD by providing educational resources and tools that can improve the experience of menstruation.

The processes for developing this tool were guided by the following models:

- Participatory Occupational Justice Framework (POJF) (See Appendix A: Participatory Occupational Justice Framework)
- Social Model of Disability

In addition to the above frameworks, this guide is structured to meet the needs of menstruators with I/DD. It follows the Guidelines for Supporting the Sexual Health of Young People Experiencing Intellectual/Developmental Disabilities. It was evaluated by the SHEIDD Resource Review Guidance Sheet and Checklist.

- 1. World Health Organization/United Nations Children's Fund. (2012). Consultation on draft long list of goal, target and indicator options for future global monitoring of water, sanitation and hygiene. https://washdata.org/sites/default/files/documents/reports/2017-06/JMP-2012-post2015consultation.pdf
- 2. Wilbur, J., Torondel, B., Hameed, S., Mahon, T., & Kuper, H. (2019). Systematic review of menstrual hygiene management requirement, its barriers and strategies for disabled people. PLOS ONE, 14(2). https://doi.org/10.1371/journal.pone.0210974
- 3. Gray, S. H., Wylie, M., Christensen, S., Khan, A., Williams, D., Glader, L. (2020). Puberty and menarche in young females with cerebral palsy and intellectual disability: A qualitative study of caregivers' experiences. Developmental Medicine and Child Neurology, 63(2), 190-195. https://doi.org/10.1111/dmcn.14698
- 4. Larson, S.K., Nielsen, S., Hemberger, K., & Klug, M.G. (2021). Addressing puberty challenges for adolescents with autism spectrum disorder: A survey of occupational therapy practice trends. The American Journal of Occupational Therapy, 75(3). https://doi.org/10.5014/ajot.2021.040105
- 5. Steward, R., Crane, L., Roy, E. M., Remington, A., & Pellicano, E. (2018). "Life is much more difficult to manage during periods": Autistic experiences of menstruation. Journal of Autism and Developmental Disorders, 48(12), 4287-4292.https://doi.org/10.1007/s10803-018-3664-0

How to Use this Guide

Use the content of this guide as you wish. The content within this guide expands from broad introductory information about puberty and periods to more detailed and specific information for the more advanced or experienced learner. Each section or subsection can be introduced all at once, in order individually, or in an order of your choice.

When viewing this document electronically, you can open the hyperlinks by selecting the text. Hyperlinks are underlined and in blue text. When viewing a printed version of this document, you can open the links by scanning the QR code with the camera app on your smartphone.

While this guide can be presented and used independently, the developers of this guide recognize the value of presenting information in a manner that is accessible to diverse learning styles. As such, this guide is recommended to be supplemented with the following materials:

- Menstrual Cup
- Menstrual Disc
- Disposable Menstrual Pad
- Reusable Menstrual Pad
- Menstrual Tampon
- Menstrual Underwear
 *See Appendix B: Price Breakdown for estimated prices of the above products

Additionally, when and if possible, use anatomically correct diagrams and 3D models when referring to reproductive anatomy to support active learning for all learning styles.

Acknowledgements

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Puberty

What is puberty?

Puberty is a natural change that happens to our bodies as we grow up. Going through puberty means that your body is starting to become more like an adult's body.





Puberty is caused by changes in your hormones. Hormones are chemicals inside your body. Hormones cause changes in your body like growing and puberty, keeping your body at a healthy temperature, or even feelings like hunger.



Everyone goes through puberty at a different time in their life. You could start puberty around 8 years old or even when you are a teenager.



It is normal to have questions about puberty. It can be helpful to ask an adult that you trust about puberty. You do not have to go through these changes alone.



Watch these videos to learn about puberty and how it can affect a person's body:

- Puberty: Am I Normal?
- Puberty and Transgender Youth
- Puberty and Finding Out Who You Are
- Top Signs Girls Are in Puberty
- Top Signs Boys Are in Puberty

These videos were found on the AMAZE YouTube page. Scan this QR code to access the AMAZE YouTube video library.

Changes: The changes happening in your body during puberty can make you look or feel different. Everyone's body goes through puberty differently. You will not have the same exact changes as your friends, family, or other people your age. Here are some changes that might happen during puberty:

Hair: Your hair may become thicker or darker during puberty. You may see more hair on your body including pubic hair and armpit hair. Pubic hair is the hair that grows between your legs on and near your genitals. Growth Spurt: You may grow taller, gain weight, and/or grow larger muscles.

Breasts: Breasts are sometimes called boobs. They are round collections of fat that form behind your nipples on your chest. Some people choose to wear a bra or binder during this time.

Acne: Acne or pimples may show up on your skin on your face or parts of your body like your back or chest.

Sex Organs: If you have a penis and testicles, they may grow larger during puberty. If you have a uterus, you will begin your period during puberty. Menstruation:

Menstruation is the same thing as having a period. People who have a uterus start their period a few years after they have started puberty.

Feelings: Your feelings, thoughts, mood, or emotions can change during puberty for many reasons. This is normal. It can help to talk about your emotions with people that you trust. Voices: Your voice may get deeper during or after puberty. **Changes:** The changes happening in your body during puberty can make you look or feel different. Everyone's body goes through puberty differently. You will not have the same exact changes as your friends, family, or other people your age. Here are some changes that might happen during puberty:

Voices: Your voice may get deeper during or after puberty.

Hair: Your hair may become thicker or darker during puberty. You may see more hair on your body including pubic hair and armpit hair. Pubic hair is the hair that grows between your legs on and near your genitals. Menstruation: Menstruation is the same thing as having a period. People who have a uterus start their period a few years after they have started puberty.

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External Reproductive Anatomy for People with a Vulva

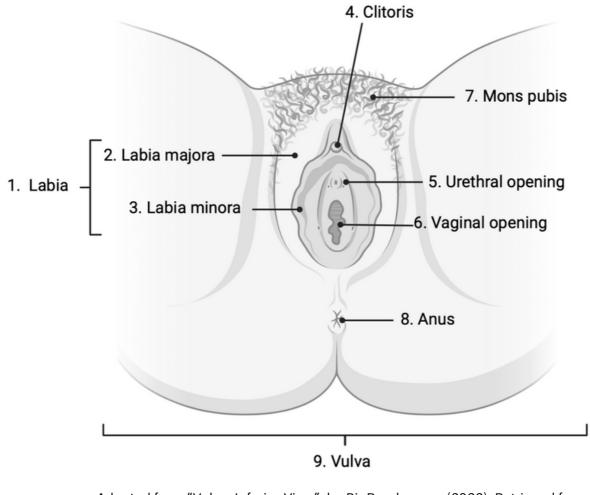
1. Labia	Folds of skin that protect the vaginal and urethral openings. There are two parts of the labia: the labia majora (2) and the labia minora (3).
2. Labia Majora	The outside labia.
3. Labia Minora	The inner labia.
4. Clitoris	The most sensitive part of your vulva. The clitoris serves to provide sexual pleasure.
5. Urethra *see urethral opening	Urine, or pee, travels through the urethra and out of the urethral opening.
6. Vagina *see vaginal opening	The vagina connects the cervix to the vulva. The vaginal opening is a passageway for childbirth, menstrual blood, and penetration during sexual intercourse.
7. Mons Pubis	A collection of fatty tissue that covers the pubic bone. Pubic hair grows on top of it.
8. Anus	The opening at the end of the digestive tract. Feces, or poop, travels out of the anus.
9. Vulva	The entire outside part. The vulva includes the labia, clitoris, urethral and vaginal openings, anus, and mons pubis.

Watch this video to learn about reproductive anatomy for people with a vulva:

• Anatomy: Assigned Sex at Birth (Female)



External Reproductive Anatomy for People with a Vulva



Adapted from "Vulva: Inferior View", by BioRender.com (2023). Retrieved from https://app.biorender.com/biorender-templates

Watch this video to learn about reproductive anatomy for people with a vulva:

• Anatomy: Assigned Sex at Birth (Female)



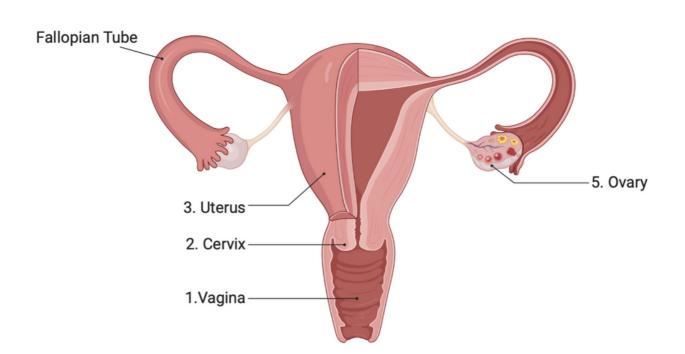
Internal Reproductive Anatomy for People with a Vulva

1.Vagina	The vagina connects the cervix to the vulva.
2. Cervix	The cervix is the lower end of the uterus that connects the uterus to the vagina.
3. Uterus	The uterus is a hollow and pear-shaped organ that is connected to the vaginal canal by the cervix and the fallopian tubes.
4. Fallopian Tubes	There are two fallopian tubes. They connect the ovaries to the uterus. An egg travels from the ovaries through the fallopian tubes to the uterus.
5. Ovaries	There are two ovaries. They produce eggs and reproductive hormones.

Watch this video to learn about reproductive anatomy for people with a vulva:

• Anatomy: Assigned Sex at Birth (Female)





Internal Reproductive Anatomy for People with a Vulva

Adapted from "Female Reproductive Anatomy", by BioRender.com (2023). Retrieved from https://app.biorender.com/biorender-templates

Watch this video to learn about reproductive anatomy for people with a vulva:

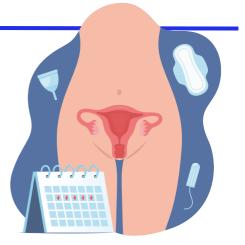
• Anatomy: Assigned Sex at Birth (Female)



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What is a period?

A period naturally happens for people with a vulva who have started puberty. A period is sometimes called menstruation. Menstruating is the same thing as having your period.



Everyone starts their period at different ages. People usually have their first period after their breasts and pubic hair have begun to grow. The scientific name for the very first period that you have is "menarche".

Why do periods happen?

Changes in hormones cause periods to happen. The hormones change to prepare the body for pregnancy. If a pregnancy happens, a period will not start. If a pregnancy does not happen, a period will start.



Hormones cause the lining of the uterus to build up or thicken. Over time, the thickened lining sheds. When the lining sheds, a small amount of blood, mucus, and cells begin to flow out of your vagina. This is your period.



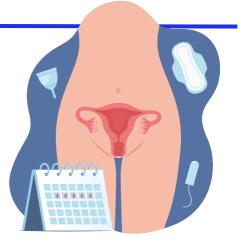
Periods usually last for 3-7 days and happen about one time every month. It is normal to sometimes skip your monthly period for the first 2-3 years after having your first period.

Watch this video about what a period is and why they happen: <u>All About Getting Your Period</u>



Symptoms of Periods

A period is a natural and healthy process. Everyone experiences periods differently, but some people have mild period symptoms.



Common Period Symptoms

- Fatigue
- Food cravings
- Cramps
- Acne
- Bloating

- Mood or behavior changes
- Joint pain
- Difficulty sleeping
- Tender breasts
- Lower back pain



Contact your doctor if you experience period symptoms that impact your participation in daily activities. The following symptoms should be reported to your doctor:

- worsening cramps
- cramps accompanied by increased menstrual flow
- pain without relief

Periods and Pain

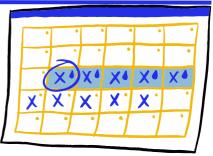
A period is a natural and healthy process. Mild discomfort is normal during periods, but contact your doctor if your pain worsens or if you are not able to find relief for pain.



Pain Management Strategies

- Leisure: If tolerable, engage in normal routine or enjoyable activities to distract attention from discomfort.
- Heat: Applying heat to the abdomen can be soothing for menstrual cramps. The heat relaxes your muscles. You can purchase a heat pack or make a heat pack. Fill a water bottle with hot water, slip a towel over it, and place it against your skin.
- Massage: Gentle massage can be soothing to your nervous system and muscles. You can go to a spa for a professional massage, use massage tools on yourself at home, or ask an adult that you trust to provide gentle massage. If you are sensitive to touch, massage may not be the best option for you.
- Gentle exercise: Exercise can relieve stress and improve fatigue, bloating, and/or cramps. If you can tolerate exercise, try yoga or going for a walk. However, if you are in too much pain to move your body, contact your doctor and rest.
- **Deep breathing:** Deep breathing exercises can be relaxing. They calm down the body. You can use props or worksheets that help with deep breathing.
- Over-the-counter medications: Over-the-counter pain medications such as ibuprofen can sometimes provide pain relief.

When you are on your period, you are expected to use products that absorb the period fluid. If you do not use these products, period fluid could leak through your clothes. The best way to avoid this is to be prepared by knowing when your period will start.



Planning for Periods

- Although it is impossible to know exactly when your period will start, you can get an estimate of what day you might begin your period.
 - Periods happen every 21-35 days.
 - Your body might feel differently when you go through different phases of your menstrual cycle. It might be helpful to track or document these changes and feelings so that you know what to expect. You might like to track your:
 - symptoms
 - heaviness of flow
 - duration of period
 - successful reliefs
 - You can use a calendar or application on your smartphone to track your periods. Here is a list of free period-tracking apps:
 - Flo
 - Clue
 - MyFlo
 - MagicGirl
- If you believe that your period might be coming soon, it is a good idea to keep period hygiene products with you. You can even wear a pad or period underwear before your period has started.
- For caregivers: You can use nonverbal communication strategies to give your young person hints that their period is coming soon. Play soothing music, provide massage, or place period hygiene products in sight.

Managing Periods

 It is normal to lose between 2-3 tablespoons of blood during your period, but some people lose more period fluid compared to other people. This is sometimes called your flow. If you have a heavy flow,



you lose more fluid on your period. If you have a light flow, you lose less fluid on your period.

Period Hygiene Products

- When you have your period, you are expected to use products that absorb the period fluid. If you do not use products to absorb the fluid, it could leak through your clothing and cause messes.
- There are many different types of period hygiene products that you can use. You may like to use some types of products more than others. Everyone has different preferences. Some factors to consider when choosing products include:
 - comfort

ease of use

style

level of absorbency

purchasing availability

environmental impact

cost

Watch these videos to learn about different types of period hygiene products:

<u>Period Hygiene: Tampons,</u>
 <u>Pads and Menstrual Cups</u>



<u>An introduction to period</u>
 <u>products for children with</u>
 <u>autism and intellectual</u>
 <u>disability</u>



Period Hygiene Products

Use the table below to explore and learn about a variety of period hygiene products

Disposable Menstrual Pad: A

disposable menstrual pad is soft and absorbent. It collects blood that comes out of your vagina. The back of the pad has a sticky side that attaches to your underwear. They can be used one time.

Reusable Menstrual Pad:

Reusable menstrual pads are soft and absorbent cloth pads. They collect blood that comes out of your vagina during your period. They are held in place with wings that have snap buttons on them. You have to wash the pad before you can reuse them.

Period Underwear: Period underwear are underwear that have moisture-wicking fabric that absorb period fluid. They look and act a lot like regular underwear but stop blood from leaking onto your clothes.



Period Hygiene Products

Use the table below to explore and learn about a variety of period hygiene products

Menstrual Cup: A menstrual cup is a flexible, funnel-shaped cup that is inserted into your vagina to collect period fluid. Menstrual cups are reusable.

Menstrual Disc: A menstrual disc is a flexible, disc-shaped product that is inserted into your vagina to collect period fluid. There are reusable or disposable menstrual discs on the market.

Tampon: A tampon is a "plug" of soft and absorbent material. A tampon is inserted into your vagina to collect blood. They can be used one time.

Provider note: The products above are inserted into the vagina. These tasks require good body positioning, coordination, functional cognition, and understanding of anatomy. If a young person is having challenges in these areas but would like to use one of the options above, consider providing

Disposable Pads

- A disposable menstrual pad is soft and absorbent. It collects blood that comes out of your vagina. The back of the pad has a sticky side that attaches to your underwear. They can be used one time.

How to Put on a Disposable Pad

- 1. Find a pad and go to the bathroom.
- 2. Wash your hands.
- 3.Go to the toilet. Pull your bottoms (pants and underwear) to your knees and sit down.
- 4. Remove the pad from its packaging. Unfold the pad.
- 5. *If you are already wearing a used pad,* remove it from your underwear. Roll it up and wrap it in the packaging of your new pad. Throw it in the trash bin. Never flush a pad down the toilet.
- 6. Peel the paper from the back of the pad.
- 7. Place the sticky back of the pad on your underwear.
- 8. *If your pad has wings*, peel off the paper from the wings. Fold the wings around your underwear.
- 9. Throw away any packaging into the trash bin.
- 10. Pull up your underwear and bottoms.
- 11. You are done! You have put on a pad. Wash your hands before you leave the restroom. Remember to change your pad frequently.

Watch this video to learn more about using pads:

 An introduction to using pads for periods for children with intellectual disability and autism
 SCAN ME



Special Considerations: Disposable Pads



- Use marker on the undewear to show where the pad should be placed.
- A pad needs to be removed every 4-8 hours depending on your flow.
- You will see period fluid collect on the pad. This can help you to see if the pad is full and needs to be changed. However, seeing the period fluid can feel scary for some people. Remember that having your period is healthy and normal. Try a different type of product if this feels too scary.
- A disposable menstrual pad is put into the garbage after use.
- Pads come in different sizes and levels of absorbency.
- Pads soak up liquids. They cannot be worn while swimming because they will swell up.
- The pad (usually a cotton material) sits against your skin. This can feel uncomfortable for some people, especially at first. Try on pads before menarche or try thinner pads at first to get used to the feeling on your skin.
- Some pads are scented. The scent can be overwhelming for some people. The purpose of the added scent is to cover up odors from the period fluid. Periods are not dirty, but a foul smell can happen if you wear your pad too long. Remember to change your pad frequently.

Watch this video to learn more about using pads:

 An introduction to using pads for periods for children with intellectual disability and autism



Reusable Menstrual Pads

 Reusable menstrual pads are soft and absorbent. They are usually made of cloth. They collect blood t that comes out of your vagina during your period. They are h held in place with wings that have snap buttons on them. You have to wash the pad before you can reuse them.

How to Use a Reusable Menstrual Pad

- 1. Find a pad and go to the bathroom.
- 2. Wash your hands.
- 3. Go to the toilet. Pull your bottoms (pants and underwear) to your knees and sit down.
- 4. *If you are already wearing a used pad,* remove it from your underwear. Roll it up and place it in a wet bag.
- 5. Place the pad on your underwear. Secure the wings of the pads around your underwear.
- 6. Pull up your underwear and bottoms.
- 7. You are done! You have put on a pad. Wash your hands before you leave the restroom. Remember to change your pad frequently.

Watch this video to learn about reusable menstrual pads:

<u>Reusable Cloth Pads for Beginners</u>



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Special Considerations: Reusable Menstrual Pads

• Compared to disposable products, investing in reusable menstrual pads can save money long-term because you will not have to re-purchase them as frequently.

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- Reusable menstrual pads come in different colors and patterns. It may be easier to find gender-neutral reusable menstrual pads compared to traditional disposable pads found in stores.
- Dark or black reusable menstrual pads can be helpful for camouflaging the sight of blood.
- Quality reusable menstrual pads can be just as absorbent as disposable pads. They should be changed every 4-8 hours depending on your blood flow.
- Reusable pads do not have the same type of sticky surface that disposable pads have. Instead, the wings usually have snap buttons. The snap buttons require more fine motor strength and dexterity than sticky wings.
- Reusable pads are not as easily accessible as disposable pads or tampons. Most people order them online.
- Using reusable pads requires extra care. They need to be washed (either hand washed or in the machine depending on the type). If you change your pad away from home, you have to keep the used pad with you. Used pads can be stored in "wet bags" until they can be washed and cleaned.

Watch this video to learn about reusable menstrual pads:

<u>Reusable Cloth Pads for Beginners</u>



Period Underwear

 Period underwear are underwear that have moisture-wicking fabric that absorb period fluid. They look and act a lot like regular underwear but stop blood from leaking onto your clothes.



How to Use Period Underwear

- 1. Period underwear can be worn like regular underwear.
- 2. Find a clean pair of period underwear.
- 3. Go to the bathroom and go to the toilet. Pull your bottoms (pants and underwear) down to your knees. Sit on the toilet.
- 4. Remove the underwear that you are already wearing.
 - a. You may need to take off your shoes to make it easier to slip your feet through your pants and underwear.
 - b. Put your used underwear into a wet bag.
- 5. Put on your clean underwear. Put your pants and shoes back on.
- 6. You are done! You have put on your period underwear. Remember to change your underwear frequently. Wash your hands before leaving the restroom.

Watch this video about period underwear: <u>An introduction to</u> period underwear for children with intellectual disability and autism



Special Considerations: Period Underwear

- Most period underwear can be washed in a washing machine cold water on a delicate setting with mild detergent. You can even wash them with other clothes. You can help prevent stains by rinsing with cold water after being used. Check the packaging of your underwear for specific drying instructions.
- You can find adaptive period underwear online that have side openings to make removing and changing the underwear easier. The side openings usually have snap buttons.
- Period underwear comes in different colors, patterns, and styles. You can find gender-neutral period underwear online.
- Period underwear is not as easy to find in convenience stores compared to tampons or pads, but you will find a variety of period underwear options online.
- Purchasing period underwear can save money in the long run compared to purchasing disposable period products.
- Period underwear can be used in place of other period products. However, some people who have heavier period flow will wear period underwear for extra protection while also using an insertable menstrual product like a tampon.
- Period underwear have different levels of absorbency. Some types can absorb up to one tampon's worth of period fluid. If you have a heavier flow, you will need to change your underwear more frequently.
- Depending on the color of your period underwear, you might see period fluid and blood collect onto the underwear. Being able to see the blood collect can be helpful for knowing when to change the underwear. Seeing the blood can feel scary for some people.
 Sometimes it is helpful to remember that having your period is healthy and normal. The blood does not mean that you are hurt. If it feels too scary to see the period fluid, you can use darker underwear that will camouflage the fluid.

Watch this video to learn more about period

underwear: An introduction to period underwear for children with intellectual disability and autism



Menstrual Cups

• A menstrual cup is a flexible, funnel-shaped cup that is inserted into your vagina to collect period fluid. Menstrual cups are reusable.

How to Use a Menstrual Cup

- 1. Go to the bathroom and wash your hands.
- 2. Go to the toilet. Pull your bottoms (pants and underwear) down to your knees.
- 3. *If you are already wearing a menstrual cup,* use your fingers to locate the stem of your cup inside your vagina. Do not pull on the stem. Locate the ribbed base of your cup just above the stem.
 - a. Hold the base of the cup. Slowly wiggle the cup out of your vaginal opening.
 - b. Empty the cup into the toilet. Rinse the cup in cold water. Use warm water and unscented soap to wash the cup. Dry the cup with toilet paper.
 - c. You are ready to insert the cleaned cup.
- 4. Fold the cup. It is flexible enough to be folded into a small and narrow shape.
- 5. Use your other hand to hold your labia apart. Gently insert the cup into your vaginal opening until it is fully inside of your vagina.
- 6. Gently pull on the cup to make sure that there is a suction-like seal. You are done! You have inserted a menstrual cup. Remember to change your cup frequently. Wash your hands before leaving the bathroom.

Watch this video about menstrual cups: An introduction to

menstrual cups for children with intellectual disability and autism





Special Considerations: Menstrual Cups

- Change your menstrual cup every 10-12 hours. Menstrual cups usually do not need to be changed as quickly as pads or tampons because they can hold more fluid.
- Compared to disposable products, investing in reusable menstrual cups can save money long-term because you will not have to re-purchase them as frequently. They can last for several years depending on the brand or if you take good care of them or not. You should purchase a new cup if you see holes or tears on yours.
- Inserting, removing, and cleaning a menstrual cup can be tricky. You can practice and build skills to help with learning how to do these tasks. You can also use different types of products.
- Your reusable menstrual cup can be rinsed between uses while on your period. Sanitize the menstrual cup in boiling water for 3-5 minutes after your period is finished.
- You can swim while using a menstrual cup.
- You will not be able to see the period fluid collect.
- When inserted correctly, you will not feel the menstrual cup throughout the day.

Watch this video about menstrual cups: <u>An introduction to</u> <u>menstrual cups for children with intellectual disability and autism</u>



Menstrual Discs

• A menstrual disc is a flexible, disc shaped product that is inserted into your vagina to collect period fluid. There are reusable or disposable menstrual discs on the market.

How to Use a Menstrual Disc

- 1. Go to the bathroom and wash your hands.
- 2. Go to the toilet and pull down your bottoms (pants and underwear) down to your knees.
- 3. *If you are already wearing a menstrual disc,* put a finger into your vaginal opening. Slide your finger inside your vagina until you feel the disc.
 - a. Hold onto the rim of the disc. Slowly pull the disc out. b. Empty the cup into the toilet.
 - i. *If you have a disposable disc,* wrap it in toilet paper and throw it away in the trash bin. Never flush a menstrual disc in the toilet.
 - ii. If you have a reusable disc, rinse it in cold water.
 Use warm water and unscented soap to wash the disc. Dry the disc with toilet paper. You are ready to insert the clean disc.
- 4. Use one hand to pinch and fold the disc. It is flexible enough to be folded into a narrow shape that can be inserted into your vagina.
- 5. Use one hand to hold your labia apart. Gently slide the disc into your vagina with your other hand. Gently tuck the rim of the disc behind your pubic bone.
- 6. You are done! You have inserted a menstrual disc. Remember to change your disc frequently. Wash your

hands before leaving the restroom. Watch this video about menstrual discs:

How to Insert a Menstrual Disc



Special Considerations: Menstrual Discs



- When inserted correctly, you will not feel the menstrual disc throughout the day.
- Some brands have options like strings, loops, or notches in them to make removing the disc easier.
- Menstrual discs can be worn safely for up to 12 hours.
- You can swim while using a menstrual disc.
- Inserting, removing, and cleaning a menstrual disc can be tricky. You can practice and build skills to help with learning how to do these tasks. You can also use different types of products.
- Reusable menstrual discs need to be cleaned. They usually need to be rinsed and washed with a mild cleanser between uses. Sanitize your menstrual disc after your period is finished by placing the disc in boiling water for 3-5 minutes. Read the packaging for specific cleaning instructions because each brand may have different requirements.
- Read the packaging of your reusable menstrual disc to find out when you should replace your disc. Some menstrual discs can last up to 5-10 years with proper care.
- You can have penetrative vaginal sex while wearing a menstrual disc.
- Purchasing reusable menstrual discs can save money in the long run compared to purchasing disposable period products.

Watch this video about menstrual discs:

How to Insert a Menstrual Disc



Tampons

 A tampon is a "plug" of soft and absorbent material. A tampon is inserted into your vagina to collect blood. They can be used one time.



How to Use a Tampon

- 1. Find a tampon and go to the bathroom.
- 2. Wash your hands.
- 3. Go to the toilet. Pull your bottoms (pants and underwear) to your knees and sit down or squat toward the toilet.
- 4. *If you are already wearing a tampon,* gently pull on the string to remove the tampon from your vagina. Wrap the used tampon in toilet paper and toss it in the trash bin. Never flush your tampon down the toilet.
- 5. Remove the tampon from its packaging.
- 6. Use your dominant hand to hold the applicator. Keep your hand on the smaller part of the applicator.
- 7. Gently put the applicator inside of your vagina at a slight angle. Aim toward your lower back. Continue to slowly insert the applicator until your finger touches your vulva.
- 8. Use your pointer finger to gently push the plunger all the way. This will release the tampon.
- 9. Pull the applicator out. A string will be sticking out of your vagina.
- 10. Throw away the applicator into the trash bin.
- 11. You are done! You have inserted a tampon. Wash your hands before leaving the restroom. Remember to change your tampon frequently.

Watch this video about tampons: <u>An introduction to using</u> tampons for children with intellectual disability and autism



Special Considerations: Tampons

- A tampon is disposable. It is thrown into the garbage after use.
- If inserted correctly, you will not feel the tampon throughout the day.
- You can swim while wearing a tampon because the absorbent material does not come into contact with the water.
- You will not see period fluid collect onto the tampon until you remove it.
- Inserting and removing a tampon can be tricky. You can practice and build skills to help with learning how to do these tasks. You can also use different types of products.
- There are a variety of tampon sizes and levels of absorbency. Light or lower absorbency tampons are easier to insert because they are smaller. However, they collect less period fluid.
- A tampon needs to be removed every 4-8 hours depending on your blood flow.
- Some tampons are scented. The scent can be overwhelming for some people. The purpose of the added scent is to cover up odors from the period fluid. Periods are not dirty, but a foul smell can happen if you wear your tampon too long. Remember to change your tampon frequently.
- If you have difficulty gripping the tampon string for removal, tie a loop at the end of a tampon string.

Watch this video about tampons: <u>An introduction to using</u> tampons for children with intellectual disability and autism



Period Hygiene Kit

What is a period hygiene kit?

 A period hygiene kit is a small bag or pouch that you can make to use when you need to change your period hygiene products.



- You can keep one or several kits anywhere that you would like, including your vehicle, school, or work.
- Some people like to carry the kit to the bathroom every time they need to change their period hygiene products to keep other people from seeing things like their tampons or pads. It is okay to keep these private.
 Remember that having a period should not make you feel embarrassed. It is healthy and normal!
- Period hygiene kits can be helpful o have if you begin your period earlier than you expected to.

What to put in a period hygiene kit:

Your kit should have items that you like to use while on your period. Here are some items that some people like to keep in their kits:

- Period hygiene products: tampons, pads, period underwear, menstrual discs, menstrual cups
- A clean pair of underwear
- Wet wipes
- Over-the-counter pain medications

What else would you put into your kit? ____

Period Hygiene Products: Sensory Strategies

• Touch:

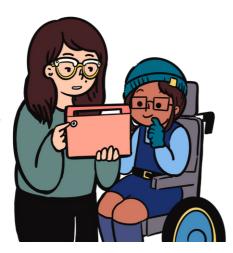
- The feeling of pads on the skin can be distressing to some people, especially for people who are sensitive to touch. Try to gradually introduce the material to the skin.
 - Start with thinner pads or panty liners. Work your way up to more absorbent pads if tolerated.
 - Practice wearing pads before menarche occurs.
- Use period underwear or hygiene products that are inserted into the vagina (tampon, disc, cup) if the feeling of pads against the skin is too distressing.
- If wet touch is tolerable and comforting, try wet wipes for cleaning and wiping the perineal area. Microwave the wet wipes (at least 5 at a time) in a sealed zip lock bag for 5 seconds.
- Smell:
 - Explore preferences for scented versus unscented disposable pads and/or tampons.
 - If tolerable, use relaxing essential oils to cover up non-preferred smells in the restroom.
- Sight:
 - Use dark/black reusable pads or underwear to minimize the visibility of period fluid.
- Sound:
 - Some disaposable menstrual products come in loud packaging that can trigger auditory sensitivities.
 - Try brands that use thin fiber packaging that makes less noise.
 - Have a support person place the pad onto clean underwear.
 - Public restrooms can be a loud place. This can be challenging for people with auditory sensitivities.
 - Put stickers or sticky notes on the sensor of automatic toilets in public restrooms.
 - Find and consistently use a restroom at school that is more private or quiet. Familiarity and privacy can be comforting.

Periods and Communication



- Ensure that a young person who uses an augmentative and alternative communication (AAC) device has access to phrases and words that allow them to communicate their needs or symptoms, like pain.
- If you are providing assistance to a young person with menstrual hygiene tasks, tell them how you will help them. Facilitate speech and language production by verbalizing phrases while you complete tasks. For example, say, "washing your hands" while washing your hands.





 Use a visual schedule to provide young people with a predictable list of expected behaviors. A visual schedule can be helpful for an entire daily routine or for individual tasks, like changing a pad.

Periods and Visual Supports

Visual supports use images or graphics to communicate a message. Some people benefit from using visual supports to help with participating in routines, schedules, or activities. Visual supports can be customized to best support the person using them. For menstrual hygiene, visual supports can help a person understand what they are expected to do. Visual supports can be beneficial for:

- impulse control
- memory
- sequencing
- attention
- confidence

planning

organization

self-regulation

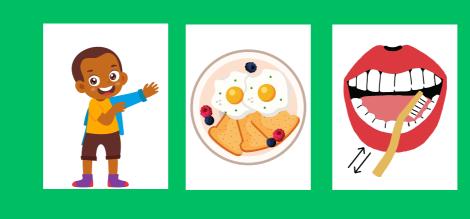
Some examples of visual supports include first/then charts, visual schedules, or social stories. Read more about them below:

 A first/then chart is a simple visual aid that shows the "first" thing that will be done followed by what will happen after or "then". First/then charts commonly use a preferred activity in the "then" spot as a motivation to do what is "first", but can also be used to teach the steps to an activity. The first/then chart shown here tells a person that they will first use the toilet, then wash their hands.

Periods and Visual Supports

 A visual schedule uses images, usually on cards, that show a sequence of steps for an activity or routine. Some people benefit from physically moving the cards to an "all done" pile after the step is completed. The visual schedule shown here shows the steps to a morning routine. A person using this schedule will see that they will first get dressed, then eat breakfast, then brush their teeth.

MORNING ROUTINE



• Social stories are a type of visual aid that use words and images in the form of short stories or books. Social stories can be helpful for presenting information about expected social behaviors. You can find a variety of social stories that talk about puberty and periods online.



Periods and Visual Supports

The resources below show examples of visual supports for periods and menstrual hygiene management:

- Story About When to Change My Pad
- Story About Getting My Period
- Story About How to Change My Pad



These resources were developed to be used as social stories, but you can be creative with how you use them. Here are some tips for using these visual supports:

- Print out the page. Read each box out loud. Look at and describe the images in each box. Then, introduce the activity. Talk about the social story that you read while doing the activity.
- Print out the page. Cut each box out. Laminate the boxes to make them more durable. Use velcro or magnets to attach each box to a board or wall. Move each box to an "all done" column.
- Write out or draw out your own visual schedule on a dryerase board. You can use the steps included in these social stories as inspiration for your own schedule or story.
- Be consistent about how you use your visual supports. Use the same type of visual supports at home and at school.

Periods and Occupational Therapy

How can an occupational therapist help?

 Occupational therapists are trained to improve health and quality of life by addressing the barriers that impact participation in daily activities, like managing menstrual hygiene.



An occupational therapist can assist with improving your experiences with menstrual hygiene management by providing family-centered, strengths-based interventions in areas like:

- education about menstruation and puberty
- socioemotional health
- functional cognition supports
- positioning and adaptive seating
- sensory-based supports
- physical comfort
- behavioral supports
- social skills supports
- medication management
- functional communication supports
- task-specific training for menstrual hygiene tasks
- task-specific adaptations
- independence with prerequisite skills (dressing, toileting, hygiene and grooming)
- family and caregiver training

Medical Management of Menstruation

Some people choose to pursue medical methods for managing periods. Speak with your doctor about your concerns regarding the management of periods to see if medical methods are right for you.



When making decisions about medically managing menstruation, these factors should be considered and prioritized:

- Patient autonomy and shared decision-making: The person who is menstruating is the most important person on the healthcare team. It is critical to include the young person in the decisions that affect them.
- Anticipatory guidance: The transition to having periods can be made easier with anticipatory guidance. Begin the conversation early to gain the skills that are required.
- Counseling: Before resorting to medications or procedures to manage periods, extensive counseling must occur. Counseling must include information about potential side effects, benefits, and/or risks.
- Patient benefit versus caregiver convenience: Before choosing to medically suppress periods, ask who will be primarily benefitting from this choice. The primary outcome of this decision should be improved quality of life for the young person.

Periods and Support People

- All support people, including but not limited to teachers, healthcare providers, parents, or peers, can play a role in supporting a young person in knowing about periods. Provide consistent guidance across groups.
- Do not assume that a young person has already received the comprehensive and holistic education about their period that they deserve.
- Educate yourself. Learn about puberty and periods so that you can comfortably answer the questions that a young person asks you.
 Provide a safe space for asking questions.
- Check with your school about their policies for assisting with toileting tasks at school.
- Establish clear expectations for support people who are assisting with menstrual hygiene management. Clear expectations can help young people recognize and report abuse.
- If you are providing physical assistance for menstrual hygiene tasks:
 - Practice proper body mechanics to protect your own body. It may be easier to complete tasks like putting on pants or underwear in bed.
 - Tell the child how you are going to help them before and during. Offer choices and ask for consent.
- Take a young person's concerns seriously. A person may confide in you with reports of pain or worries. You may be the first or only person that they feel comfortable giving this information to.

Periods and Support People: Talking About Periods

- Practice early and often. The transition to periods can be easier if you begin conversations about periods before they occur. A child could be more fearful about their period if they do not know what is happening. Children will not learn what they need to know in one conversation. A child should be able to shower, change their clothes, toilet, and wash their hands if expected to adapt to a menstrual hygiene routine.
- Use gender-neutral terminology. Not all people who menstruate are girls/women. Saying, "people who get periods", "people who menstruate", or "people with uteruses" is more inclusive to nonbinary or transgender people who menstruate. Additionally, do not refer to menstrual products as feminine products.
- Model positivity. A young person's feelings about periods can be influenced by yours. Be mindful of the language that you use. Give the child reassurance about any difficulties that they may face. Model calm attitudes in response to the young person's confusion, worries, or mistakes.
- Embrace individual differences. Everyone's period manifests itself differently. Additionally, everyone learns differently. Each person will have different goals, needs, and overall experiences. Individualize your supports to best support your young person. Provide various teaching opportunities and tools, like short videos, modeling, group lessons, or handouts.

Periods and Support People: Talking About Periods

- Use specific, accurate, and detailed examples. Use formal words for body parts to prevent confusion. Refer to anatomically correct models or physical menstrual hygiene materials when possible.
- Create a safe space. Children may feel worried, embarrassed, or confused when learning about puberty or periods. Create a non-judgemental space to ask questions. If talking with a group, it may be helpful to create and agree on rules for the group discussion at the start of the session.
- Promote autonomy. Provide plentiful opportunities to practice and build skills to improve the experience of menstrual hygiene management. All young menstruators have the right to learn about and care for their own bodies.

Period Education Resources

General Resources:

- <u>Puberty Education Kit</u>: These kits are available to check out from the Multnomah County Library. They are designed to support young people through puberty. Kits include books, teaching tools like flipbooks, and photos of puberty-related items.
- <u>Menstrual Diary:</u> Use this document to track your period and period-related symptoms.

Websites:

- <u>Planet Puberty</u>: Planet Puberty is an Australian digital resource suite designed to support people with I/DD and/or autism spectrum disorder (ASD) and their caregivers as they navigate puberty. It was co-designed by people with I/DD and/or ASD. The website has games, stories, YouTube videos, and other digital resources on the following topics: the body, feeling good, relationships, identity, and keeping safe.
- <u>AMAZE.org</u>: AMAZE is a sex education resource hub. The website is home to puberty, relationships, and sexual health resources that can support youth, parents, and educators.
- <u>Refuge Restrooms:</u> Refuge Restrooms is a trans-led website and smartphone application. Enter your location to find safe public restrooms for transgender, intersex, and gender nonconforming people.
- <u>Teachers Pay Teachers</u>: Teachers Pay Teachers is a website that has free and paid educational resources available for download. There are dozens of resources that can be used to teach about periods or menstrual hygiene management.

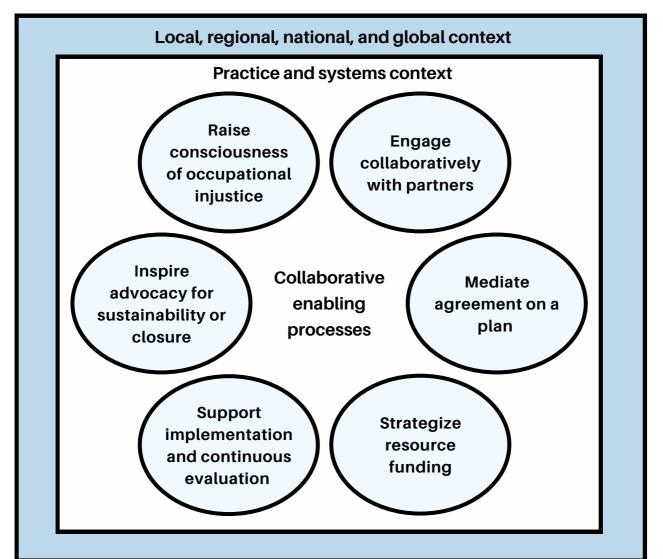
Books:

• The Autism-Friendly Guide to Periods: This book teaches the basics of menstruation. You can find it on <u>Amazon</u> or at your local library.

Smartphone Apps:

- **Refuge Restrooms:** Refuge Restrooms is a trans-led website and smartphone application. Enter your location to find safe public restrooms for transgender, intersex, and gender nonconforming people.
 - Apple: Download on the <u>App Store</u>
 - Android: Download on Google play

The Participatory Occupational Justice Framework (POJF) is a conceptual tool for doing justice. It can guide practice processes with professionals and the public with social inclusion in occupations regardless of individual characteristics as the targeted outcome. Occupational therapists who use the POJF engage in critical occupational therapy practice by challenging and reflecting on discrepancies between everyday occupational therapy practices and occupational therapy philosophy and theories. The POJF guides practice processes by promoting justice using an enabling approach that prioritizes occupation. The figure below shows the six nonlinear processes of the POJF. Each of the six processes occurs within two sets of contexts: the immediate practice and systems context and the larger scoped local, regional, national, and global context (Whiteford & Townsend, 2011).



This page is part of a period education guide, a collection of resources designed to support menstruation. See the rest of the guide here: Period Education Guide

Description of the process	Application to capstone and resource development
Raise consciousness of occupational injustices: Raise awareness among the public and professionals by directly naming occupational injustices and describing how these injustices threaten social inclusion in everyday life	 Explored occupational therapy literature and research on menstrual hygiene management (MHM) practices for youth with disabilities with an emphasis on data that included people with lived experiences of disability and menstruation Completed a needs assessment to identify what resources or processes providers are currently using to address MHM Expanded on the needs assessment by meeting with and actively listening to people with lived experiences of disability and menstruation. Used these narratives combined with literature that included the perspectives of people with lived experiences of menstruation and disability to name and describe the occupational justices that occur for people who experience disability and menstruation. This process highlighted a need to protect and defend the rights for choice, control, and autonomy around occupational engagement for youth with I/DD that menstruate. All meetings with stakeholders outside of occupational therapy included an explain menstrual hygiene management as an occupation, as well as the threats to healthy engagement in MHM for youth with I/DD.

Description of the process	Application to capstone and resource development
Engage collaboratively with partners: Promote collaborative enablement by forming and negotiating on a partnership with mutually agreed upon terms	 The population of central concern was identified early in the development process. The guide is intended to be usable by youth, caregivers, and professional support people. However, the primary recipients of the information will be youth. As such, the guide was informed by literature that included the perspectives of youth with I/DD as well as the Guidelines for Supporting the Sexual Health of Young People Experiencing Intellectual/Developmental Disabilities. Prescriptive practices were avoided throughout. Stakeholders were encouraged to share feedback, values, desires, and interests throughout the process. Plans for the guide were reviewed and modified based on this information. Although a prescriptive practice was avoided, the guide was ultimately developed to improve occupational justice for folks who menstruate with I/DD. This was agreed upon with partners. Partners were provided with information about potential opportunities and limitations related to the capstone process. Some limitations include time constraints and limited funding opportunities.

Description of the process	Application to capstone and resource development
Mediate agreement on a plan: Initiate an agreement based on common expectations regarding the goals, objectives, and outcomes that will be targeted	 Stakeholders were consulted in all stages of development. Goals and objectives were informed by all stakeholders. However, there was no formal documentation of the agreement. Pre-existing menstrual hygiene management resources and practice trends were evaluated to identify targeted outcomes as well as the current barriers to and opportunities for improvement. There were significant efforts spent in assessing and identifying the audience and location that would have the greatest collective impact. Gaps were identified in all systems that were assessed and as such, the guide was designed to meet the learning and accessibility needs of diverse audiences. The Guidelines for Supporting the Sexual Health of Young People Experiencing Intellectual/Developmental Disabilities was used as a framework for development. The SHEIDD Resource Review Guidance Sheet was used to self-evaluate the guide. Finally, surveys were sent to all stakeholders to evaluate outcomes.

Description of the process	Application to capstone and resource development
Strategize resource funding: Explore, identify, and pursue sources for funding and sustainability	 Funding was a barrier to the development of this guide. The guide was ultimately created without financial resources to improve the accessibility of the materials. However future iterations of a period education guide are encouraged to pursue funding that will support physical items to supplement the learning materials in the guide. This will be beneficial for all learners. An estimated price breakdown was created to assist with the pursuit of financial support. An EPIC SmartPhrase was developed to raise awareness of period education resources. This development was shared in a newsletter. A maintenance plan was developed for the sustainability of the period education guide. There will be a yearly review of the guide to ensure that the material (links and content) are accurate and up to date. Editing permissions were granted for future modifications. Time in the clinical setting was identified as as the most significant barrier for all stages of development. Time restrictions were a challenge for meeting with stakeholders. Additionally, providers reported that they have little time to discuss menstrual hygiene management during clinical appointments. As such, providers are limited by time constraints when accessing and implementing novel resources or intervention tools. The role that occupational therapy can play in supporting menstrual hygiene management was identified and described.

The table below describes how each of the six interconnected POJF processes guided enabling collaborative planning, implementation, continuous evaluation, and decision-making for this capstone.

Description of the process	Application to capstone and resource development	
Support implementation and continuous evaluation of the plan: Engage in critical reflexivity within the fluid and continuous implementation and evaluation processes. Revise the plan as needed.	 Revisions were made to the guide based on stakeholder feedback and concerns during the development process. Additionally, the period education guide is fluid as it is encouraged to be modified and adapted to best meet the needs of the person using the tool. All stakeholders, including the population of central concern, were consulted in all stages of development. A survey was created to gather quantitative and qualitative data about the effectiveness of the guide in enabling occupational justice for the population. 	
Inspire advocacy for sustainability or closure: Facilitate a collaborative decision making process regarding future uses of the services or program	 The guide was electronically shared with stakeholders. Some stakeholders met in virtual meetings to share their feedback and decisions about using the guide. Stakeholders who were not able to meet virtually were encouraged to participate in an anonymous survey. Strategies for using the guide were identified and described. Additionally, stakeholders were surveyed to identify their perceptions of the benefits or uses of the guide. Occupational therapy's role in addressing menstrual hygiene management in clinical practice was described and identified to inspire a collective effort of the profession to pursue occupational justice for people who experience menstruation and I/DD. 	

Reference

Whiteford, G., & Townsend, E. (2011). Participatory occupational justice framework (POJF 2010): Enabling occupational participation and inclusion. In F. Kronenberg, N. Pollard & D. Sakellariou (Eds.), Occupational therapy without borders: Towards an ecology of occupation-based practices (pp. 65-84). Elsevier.

Appendix B: Estimated Price Breakdown

Product or Material	Price
Disposable Menstrual Pad <u>Always Ultra Thin Feminine Pads with</u> <u>Wings, 126 count</u>	\$18.45
Menstrual Cup <u>DivaCup Model 1 Menstrual Cup, 1</u> <u>count</u>	\$33.11
Menstrual Tampon <u>Tampax Pearl Unscented Regular</u> <u>Tampons, 50 count</u>	\$10.47
Menstrual Underwear <u>THINX Hiphugger Period Underwear, 2</u> <u>count</u>	\$62.99
Reusable Menstrual Disc <u>Flex Reusable Menstrual Disc, 1 count</u>	\$33.22
Reusable Menstrual Pad <u>Leekalos Reusable Bamboo Menstrual</u> <u>Cloth Pads, 6 count</u>	\$13.99
Total Price	\$172.23

Note: These prices were obtained from Amazon in the summer of 2023 and are subject to change due to currency fluctuations or the site of purchase. Additionally, some of the items listed below reflect bulk quantities. While it may be helpful to keep several items in your kit while presenting them, consider donating extra supplies to other groups teaching about menstruation or to public restrooms in spaces like libraries, parks, or schools.

Appendix C: Author Biography

About the Author: Noelle Vidak, an occupational therapy student at Pacific University, developed this manual in partial completion of her doctoral experience and doctoral capstone project. Noelle is passionate about addressing barriers to engagement in occupations to improve health and quality of



life for all, but she is particularly enthusiastic about serving pediatric clients and their families. The topic of this capstone was inspired by social justice and inclusion for seemingly mundane occupations, like menstrual hygiene management, for those who experience intellectual and developmental disabilities. Noelle is enthusiastic about carrying these themes into clinical practice upon completion of her occupational therapy degree.

