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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.

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