

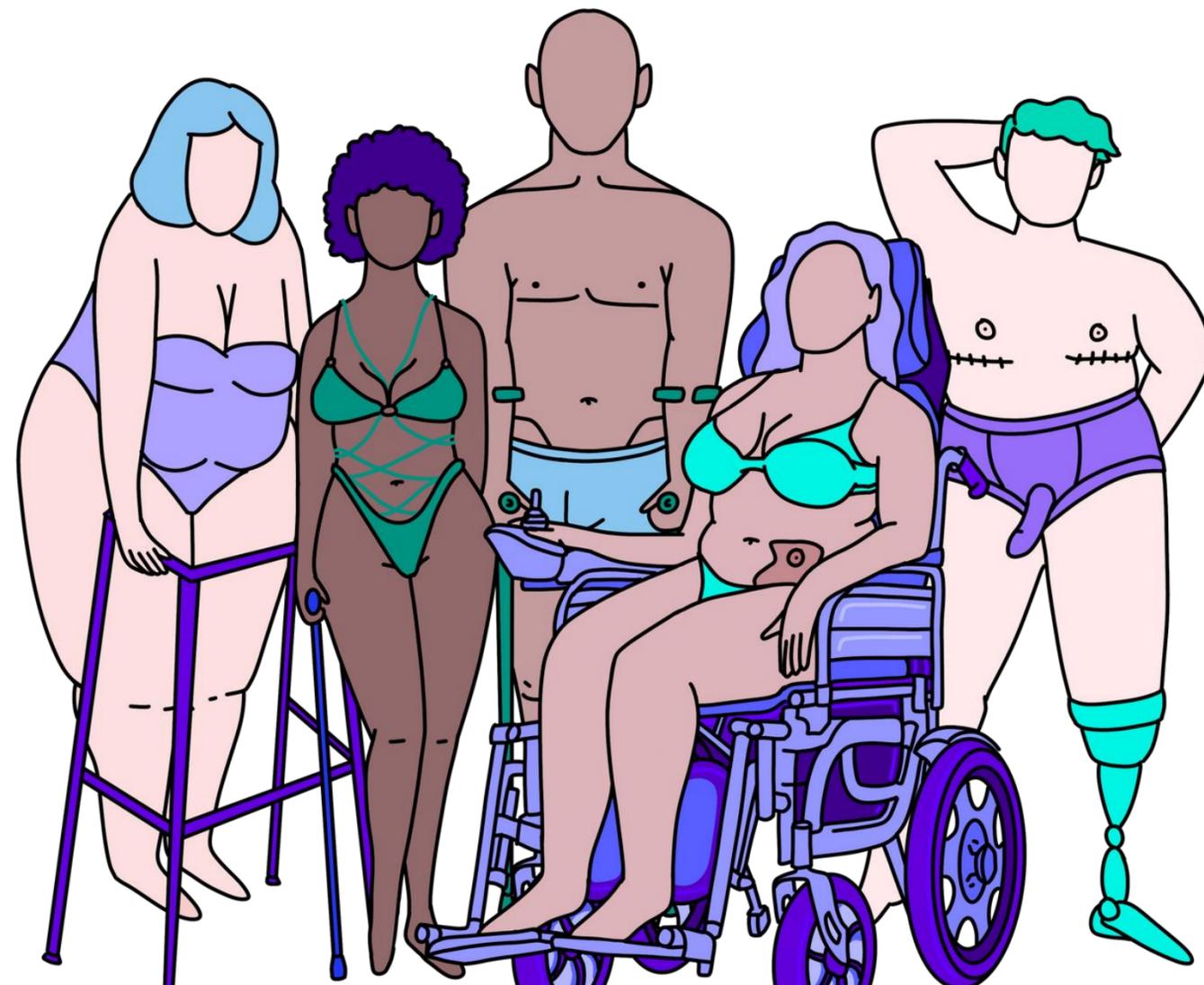
# NO TABOO

## The Sexual Experiences of Adults with Physical Disabilities Through Photovoice

### Presentation by Artemis C. Guay

In collaboration with : Isabelle Wallach (UQAM), Claudine Auger (UdeM), Fédération du Québec pour le planning des naissances, Lévis-Simon Carpentier (Ex aequo)

And five APD peer researchers: Patrick Desjardins, Éric Lapointe, Christian Lapierre, Gwendoline Lüthi and Melody Courtois



*We wish to acknowledge that this research was conducted on unceded indigenous territory. Tiohtiá:ke or Mooniyang (Montreal) is an ancestral place of gathering and exchange between many First Nations, such as the Kanien'kehá:ka of the Haudenosaunee confederation, the Wendat, W8banaki and Anishinaabe people.*

*We stand in solidarity with indigenous people who also face sexual stigmatization, in the forms of false beliefs around their sexual lives and colonialist beauty standards pushed on their bodies and minds.*

*While indigenous voices are missing from this research, we hope the work we are doing will open a path toward critical thinking in people's mind and guide them in reconsidering their biased views toward all marginalized communities on Turtle Island (Canada)*

# Sexual stigmatization of adults with physical disabilities (APD)

- Stigmatization is the process of devaluing characteristics and behaviors based on their deviation from the norm <sup>1</sup>
- Two main social perceptions stigmatize the sexual lives of APD: <sup>2-4</sup>
  - APD don't have desires for sexual activities or interactions
  - APD don't have sexual abilities to provide or receive sexual gratification
- While the sexual stigmatization APD face is well documented and deemed the main obstacle in their sexual lives, little has been done to decrease it <sup>5-8</sup>

**Following a participatory action research approach and informed by a steering committee, we aim to transform negative social perceptions of APD sexual lives**

- 1** Document the sexual experiences of adults with physical disabilities
- 2** Identify needs for specialized sexology and sexual rehabilitation
- 3** Raise awareness among health care professionals and the public about the sexual lives and needs of APD



# Photovoice methodology

- Photographies and stories can enable a nuanced comprehension of APD's lives for people who have had little to no interactions with them <sup>9-10</sup>
- Demonstrated as adequate to explore one's sexual life <sup>11-12</sup>
- Peer group discussions specifically enables critical dialogue <sup>13</sup>
- Participatory and reflexive thematic analyses will involve the steering committee as well as the photographers

## 1 women group, 2 mixed groups (n=16)

**AGE:** Between 26 and 56 years old

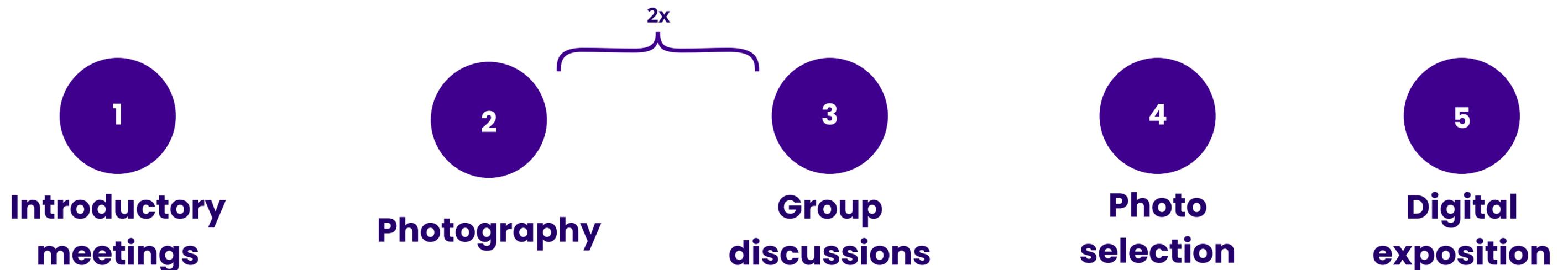
**GENDER:** 10 cis women, 4 cis men, 1 trans woman, and 1 non-binary person

**SEXUALITY:** 12 heterosexual, 4 bisexual or pansexual

**DISABILITY:** 8 congenital, 8 acquired

**RACE:** All white, except one Black woman

**LANGUAGE:** All speaking French, except one in Quebecois Sign Language



# Preliminary results – Sexualizing disability and assistive devices

Subverting ableist conceptions of desire and beauty through self-acceptance



Thalie, 37 y/o hetero woman

"It's a part of me": integrating assistive devices in sexual practices



Alain, 51 y/o hetero man, with Sonia Von Sacher, sex worker

"It's not because we're disabled that we can't" : the felt importance of showing explicit evidence of APDs having sex



Jeanne, 37 y/o hetero woman

# Preliminary results – An embodied quest toward pleasure

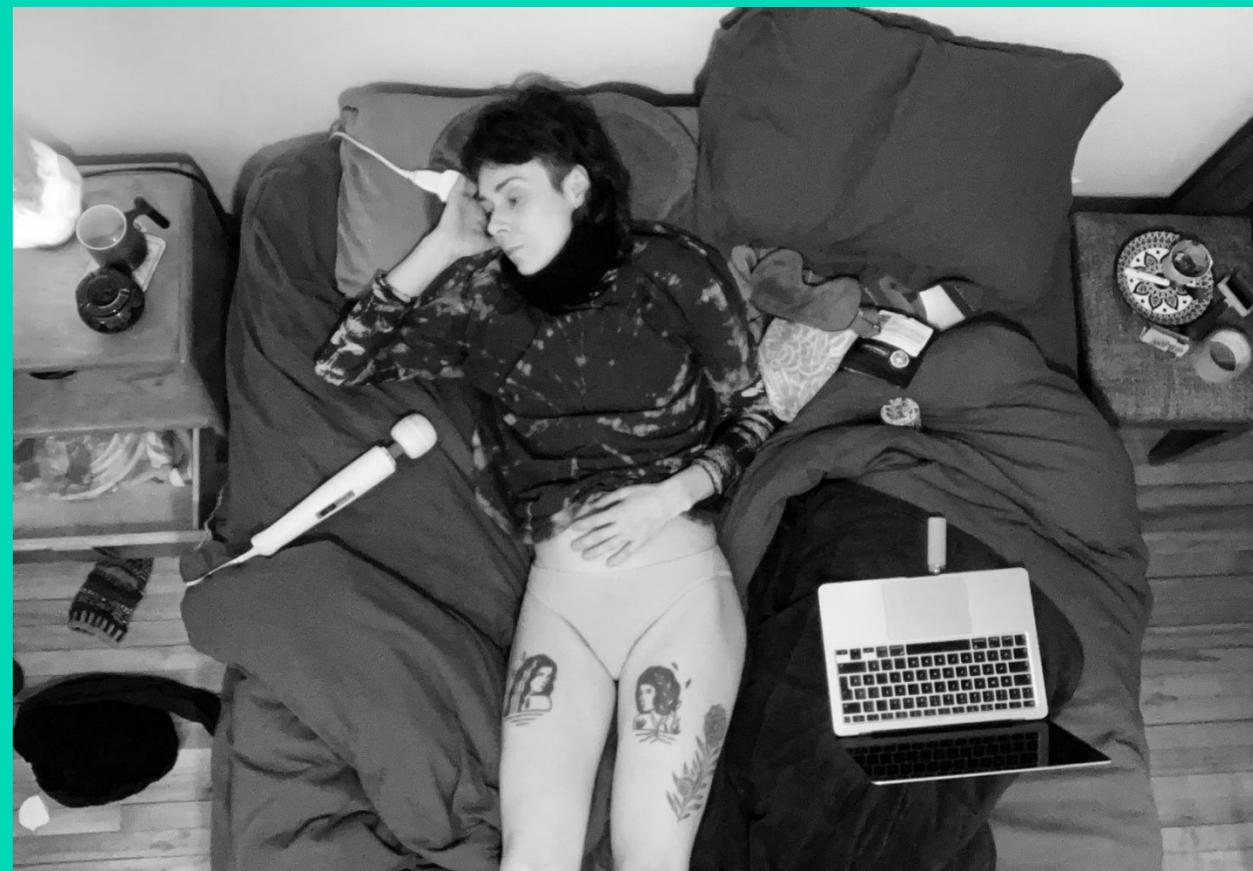
Journeys of highs and lows, “like the ocean”

“We are deserving of more”: resisting the trope of the easy disabled woman

Dualities at the interface of social norms: pleasure vs pain



Audrey, 32 y/o hetero woman, modified using Open AI



Magnesium, 42 y/o pansexual non-binary person



Georges, 53 y/o lesbian woman



Fleur, 29 y/o hetero woman

# Preliminary results – A right to access sexual services

While there weren't many photographs taken specifically to represent sexual services, these were discussed abundantly; a hidden theme, underlying many of APDs' stories...

Sexual services for APD should include safe access to sex workers and sexual assistance

Sexual assistance should go beyond sexual activities

Health care providers are deemed responsible for initiating conversations about sex and gaining appropriate training to support APD in a variety of needs

Structural changes to the current organization of sexology and rehabilitation services are needed



Québec

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- CIUSSS de l'Ouest-de-l'Île-de-Montréal - 514 363-3025, poste 2257
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**NOTE**

Tous les champs précédés d'un astérisque (\*) sont obligatoires. Un formulaire incomplet pourrait vous être retourné. Nous vous demandons de remplir le formulaire en lettres moulées s.v.p.

1. IDENTIFICATION

Identification

\*NOM : \_\_\_\_\_ \*PRÉNOM : \_\_\_\_\_

\*DATE DE NAISSANCE : \_\_\_\_\_ \*NUMÉRO DE LA CARTE D'IDENTITÉ : \_\_\_\_\_ \*EXPIRATION : \_\_\_\_\_

\*SEXE :  Masculin

\*LANGUE : \_\_\_\_\_

Langue des signes américaine (ASL)

\*NOM DE LA MÈRE : \_\_\_\_\_

\*PRÉNOM DE LA MÈRE : \_\_\_\_\_

STATUT CIVIL :  Canadien

Milieu de vie

Maison/ Appartement

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Nom de la ressource : \_\_\_\_\_

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Audrey, 32 y/o hetero woman

# Preliminary results – Positive impacts of group photovoice

Throughout the discussions, and in response to the evaluation question at the end of each sessions, positive impacts of the methodology emerged...

A welcomed rare intimate space to discuss amongst peers a subject that is still taboo

Mutual aid and guidance

An opportunity to deepen the relationship to oneself or their partners through photography and seeing their peers' photographs



Brittany, 48 y/o hetero woman

# Conclusion

- First group photovoice study on disability and sexuality with a sample exceeding 6-8 photographers and multiple rounds of photography and discussions
- Results mirror previous studies, while opening new paths of understanding
  - The process of self-acceptance and deconstructing ableism in sexuality has been reported <sup>7-8, 14-16</sup>
  - The positive integration of assistive devices in sexual practices is a novel contribution
  - Needs for sexual services are refined and show the necessity of an interdisciplinary approach, in and out of healthcare
  - Sex is political and a public health issue, maybe even more so in the case of APDs
- A particular attention to documenting the impacts of group photovoice demonstrate not only it's feasibility in the field of sex and disability, but it's unique ability to foster peer support and critical dialogue

Evaluation study to come!



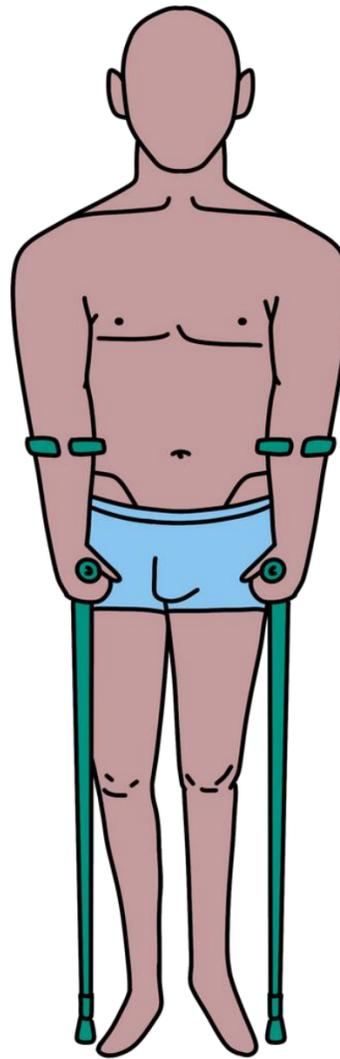
# Thank you!

If you wish to stay in touch, sign-up to our newsletter!

<https://mailchi.mp/d881075e9e75/artemis-c-guay>



We thank all the photographers involved in the project, our graphic designer Maude Bergeron from “Les folies passagères”, our collaborators and funding agencies.



# References

1. Aranda, A. M., Helms, W. S., Patterson, K. D. W., Roulet, T. J. et Hudson, B. A. (2023). Standing on the Shoulders of Goffman: Advancing a Relational Research Agenda on Stigma. *Business & Society*, 62(7), 1339-1377. <https://doi.org/10.1177/00076503221148441>
2. Brodwin, M. G. et Frederick, P. C. (2010). Sexuality and Societal Beliefs Regarding Persons Living with Disabilities. *Journal of Rehabilitation*, 76(4), 37-41.
3. Collisson, B., Edwards, J. M., Chakrian, L., Mendoza, J., Anduiza, A. et Corona, A. (2020). Perceived Satisfaction and Inequity: A Survey of Potential Romantic Partners of People with a Disability. *Sexuality and Disability*, 38(3), 405-420. <https://doi.org/10.1007/s11195-019-09601-7>
4. Pebdani, R. N. et Tashjian, A. (2021). An Analysis of the Attitudes of the General Public Towards the Sexuality of Individuals with Disabilities Through a Systematic Literature Review. *Sexuality and Disability*. <https://doi.org/10.1007/s11195-021-09700-4>
5. Guay, C., Wallach, I. et Auger, C. (2023, October 12-14). Physical disability and sexuality: a metasyntesis of the personal and environmental factors related to the lived sexual experiences of adults with physical disabilities. Canadian Sex Research Forum Annual Conference, Montreal, Canada.
6. Liddiard, K. (2021). *Theorising disabled people's sexual, intimate, and erotic lives* Dans R. Shuttleworth et L. R. Mona (dir.), *The Routledge handbook of disability and sexuality*. Routledge.
7. Nery-Hurwit, M. B., Kalpakjian, C. Z., Kreschmer, J. M., Quint, E. H. et Ernst, S. M. (2022). Development of a Conceptual Framework of Sexual Well-being for Women with Physical Disability. *Women's Health Issues*, 32(4), 376-387. <https://doi.org/10.1016/j.whi.2022.02.003>
8. Nguyen, T. T. A., Liamputtong, P. et Monfries, M. (2016). Reproductive and Sexual Health of People with Physical Disabilities: A Metasyntesis. *Sexuality and Disability*, 34(1), 3-26. <https://doi.org/10.1007/s11195-015-9425-5>
9. Labbé, D., Mahmood, A., Routhier, F., Prescott, M., Lacroix, É., Miller, W. C. et Mortenson, W. B. (2021). Using photovoice to increase social inclusion of people with disabilities: Reflections on the benefits and challenges. *Journal of community psychology*, 49(1), 44-57. <https://doi.org/10.1002/jcop.22354>
10. Wang, C. C. et Burris, M. A. (1997). Photovoice: concept, methodology, and use for participatory needs assessment. *Health Education & Behavior*, 24(3), 369-387. <https://doi.org/10.1177/109019819702400309>
11. Christensen, M. C., Capous-Desyllas, M. et Arczynski, A. V. (2020). Photovoice as a Multilevel Tool for Gender and Sexual Identity Exploration. *Families in Society: The Journal of Contemporary Social Services*, 101(2), 219-231. <https://doi.org/10.1177/1044389419889710>
12. Hunt, X., Swartz, L., Braathen, S. H., Jordan, C. et Rohleder, P. (2020). (Re)presenting the self: Questions raised by a photovoice project with people with physical disabilities in South Africa. *Disability & Society*, 35(6), 876-901. <https://doi.org/10.1080/09687599.2019.1649125> 13
13. Catalani, C. et Minkler, M. (2010, Jun). Photovoice: a review of the literature in health and public health. *Health Education & Behavior*, 37(3), 424-451. <https://doi.org/10.1177/1090198109342084>
14. Hunt, X., Braathen, S. H., Swartz, L., Carew, M. T. et Rohleder, P. (2018). Intimacy, intercourse and adjustments: Experiences of sexual life of a group of people with physical disabilities in South Africa. *Journal of Health Psychology*, 23(2), 289-305. <https://doi.org/10.1177/1359105317741761>
15. Kattari, S. (2014). Sexual Experiences of Adults with Physical Disabilities: Negotiating with Sexual Partners. *Sexuality & Disability*, 32(4), 499-513. <https://doi.org/10.1007/s11195-014-9379-z>
16. MacKeigan, T. (2021). Sexual citizenship through resistance: a movement that centers disabled women's voices. *Disability & Society*, 36(4), 656-677. <https://doi.org/10.1080/09687599.2020.1751077>