Equity and Inclusion in Pregnancy Care:

Report on the Pregnancy Outcomes and Health Care Experiences of People with Disabilities in Ontario

VIEW THE 2024 REPORT

Contents

AUTHORS

HILARY K. BROWN
GUL SAEED
LESLEY A. TARASOFF
LAURIE PROULX
KATE WELSH
KINWAH FUNG
SARAH QURESHI
ASTRID GUTTMANN
SUSAN M. HAVERCAMP
SUSAN L. PARISH
JOEL G. RAY
SIMONE N. VIGOD
YONA LUNSKY

April 2024

Publication Information

ICES

V1 06, 2075 Bayview Avenue

Toronto, ON M4N 3M5

Telephone: 416-480-4055

Email: communications@ices.on.ca

How to cite this publication

Brown HK, Saeed G, Tarasoff LA, Proulx L, Welsh K, Fung K, Qureshi S, Guttmann A, Havercamp SM, Parish SL, Ray JG, Vigod SN, Lunsky Y. Equity and inclusion in pregnancy care: report on the pregnancy outcomes and health care experiences of people with disabilities in Ontario. Toronto, ON: ICES; 2024.

ISBN: 978-1-926850-99-3

This document is available at www.ices.on.ca

Authors’ Affiliations

HILARY K. BROWN, PHD

Associate Professor, Department of Health and Society, University of Toronto Scarborough / Associate Professor, Dalla Lana School of Public Health / Adjunct Scientist, ICES

KINWAH FUNG, MSC

Senior Research Methodologist, ICES

ASTRID GUTTMANN, MDCM MSC FRCPC

Chief Science Officer, ICES / Senior Scientist, Edwin SH Leong Centre for Healthy Children, Hospital for Sick Children / Professor, Department of Pediatrics, Temerty Faculty of Medicine, University of Toronto

SUSAN M. HAVERCAMP, PHD

Professor, Wexner Medical Centre, Ohio State University

YONA LUNSKY, PHD C.PSYCH

Director, Azrieli Adult Neurodevelopmental Centre / Senior Scientist, Centre for Addiction and Mental Health / Professor, Department of Psychiatry, Temerty Faculty of Medicine, University of Toronto / Adjunct Scientist, ICES

SUSAN L. PARISH, PHD MSW

President, Mercy University

LAURIE PROULX, BCOMM

Peer Researcher, Department of Health and Society, University of Toronto Scarborough / Managing Director, Canadian Arthritis Patient Alliance / Patient inclusion in research advocate / Mother with a physical disability

SARAH QURESHI, BSC

Research Assistant, Department of Health and Society, University of Toronto Scarborough

JOEL G. RAY, MD MSC FRCPC

Clinician-Scientist, Unity Health Toronto / Professor, Department of Obstetrics and Gynaecology, Temerty Faculty of Medicine, University of Toronto / Professor, Institute of Health Policy, Management and Evaluation, University of Toronto / Adjunct Scientist, ICES

GUL SAEED, MPH

Research Assistant, Department of Health and Society, University of Toronto Scarborough

LESLEY A. TARASOFF, PHD

Postdoctoral Fellow, Department of Health and Society, University of Toronto Scarborough / Postdoctoral Fellow, Centre for Addiction and Mental Health

SIMONE N. VIGOD, MD MSC FRCPC

Head of Psychiatry, Women’s College Hospital / Professor, Department of Psychiatry, Temerty Faculty of Medicine, University of Toronto / Senior Adjunct Scientist, ICES

KATE WELSH, MED

Peer Researcher, Department of Health and Society, University of Toronto Scarborough / Disability Equity Education Coordinator, Centre for Independent Living in Toronto / Queer, disabled artist, community activist and educator / Disability-affirming mental health counsellor

Acknowledgments

ADVISORY COMMITTEE

We thank the members of the Disability and Pregnancy Study Advisory Committee for providing thoughtful input and advice throughout the study. Their insight was critical in developing the recommendations in this Report. Advisory Committee members include:

Tihana Antic, MA, Senior Policy Advisor, Ontario Ministry of Health

Melanie Basso, RN MSN, Senior Practice Leader, Perinatal, Advanced Collaborative Care Planning Program, BC Women's Hospital and Health Centre / Founding Member, Spinal Cord Injury Perinatal Interest Group

Anne Berndl, MD MSc FRCSC, Director, Accessible Care Pregnancy Clinic, Sunnybrook Health Sciences Centre / Associate Professor, Department of Obstetrics and Gynaecology, Temerty Faculty of Medicine, University of Toronto

Deborah Bluestein, MA, Therapist, Parenting Enhancement Program, Surrey Place

Gabriella Carafa, RSW MSW RSW PMH-C, Collaborative Practice Leader, Holland Bloorview Kids Rehabilitation Hospital / Psychotherapist and consultant in private practice / Mother with a physical disability

Krista Carr, BBA, Executive Vice-President, Inclusion Canada / Chair, Ministerial Disability Advisory Group

Lucy Costa-Nyman, Peer Support Coordinator, Vibrant Healthcare Alliance / Founding Member, Strength-Based Parenting Initiative / Mother with cerebral palsy

Cindy DeGraaff, BSW, Planning Services Manager, Ontario Federation of Cerebral Palsy / Member, Strength-Based Parenting Initiative

Karen Hodge, RCSW MSW, Registered Clinical Social Worker / Woman with a spinal cord injury sustained at the T1 level at the age of 15 / Wife and mother of two young children (both conceived and born post-spinal cord injury) / Founding Member, Spinal Cord Injury Perinatal Interest Group

Mandy Klein, Autistic mother and advocate

Melanie Marsden-Meyers, BSW, Accessibility and inclusion advocate / Former Project Manager and Accessibility Specialist, Springtide Resources / Founding Member, Strength-Based Parenting Initiative / Indigenous mother and grandmother who is blind

Sue Marsh-Woods, Regional Manager, Client Service, Vision Loss Rehab Ontario

Cindy Perry, PhD, Director, Analytics and Measurement, Ontario Ministry of Children, Community and Social Services

Wendy Porch, MEd, Executive Director, Centre for Independent Living in Toronto / Mother with a disability

Charlotte Pyke, MA, Project Officer, Inclusion Canada

Rebecca Wood, MA, Peer and Parenting Program Coordinator, Centre for Independent Living in Toronto

Acknowledgments

RESEARCH TEAM

We also thank the students and research staff who contributed to the Disability and Pregnancy Study. Their dedication and methodological expertise were invaluable to this research.

Adele Carty, PhD Student, Dalla Lana School of Public Health, University of Toronto

Simon Chen, Research Analyst, ICES

Caroline Kassee, MPH Student, Dalla Lana School of Public Health, University of Toronto

Momina Khan, MPH Student, Dalla Lana School of Public Health, University of Toronto

Fareha Nishat, MPH Student, Dalla Lana School of Public Health, University of Toronto

FUNDING

This study was supported by the Eunice Kennedy Shriver National Institute of Child Health & Human Development of the National Institutes of Health under award R01HD092326 and by an Ontario SPOR Support Unit EMPOWER Award. Hilary K. Brown is supported by a Tier 2 Canada Research Chair in Disability and Reproductive Health (2019-00158).

This study was also supported by ICES, which is funded in part by an annual grant from the Ontario Ministry of Health and the Ministry of Long-Term Care.

DISCLAIMER

Parts of this material are based on data and/or information compiled and provided by the Canadian Institute for Health Information. This document used data adapted from the Statistics Canada Postal CodeOM Conversion File, which is based on data licensed from Canada Post Corporation, and/or data adapted from the Ontario Ministry of Health Postal Code Conversion File, which contains data copied under license from ©Canada Post Corporation and Statistics Canada. We thank IQVIA Solutions Canada Inc. for use of their Drug Information File.

The analyses, conclusions, opinions, and statements expressed are those of the authors and do not reflect those of the funding or data sources. No endorsement by ICES or the Ontario Ministry of Health is intended or should be inferred.

The views expressed in this report do not necessarily represent the position of ICES, the University of Toronto Scarborough or the Centre for Addiction and Mental Health.

About the Organizations Involved in this Report

UNIVERSITY OF TORONTO SCARBOROUGH

Founded in 1827, the University of Toronto (U of T) is Canada's top university with a long history of challenging the impossible and transforming society through the ingenuity and resolve of its faculty, students, alumni and supporters. An anchor institution in the eastern Greater Toronto Area, U of T Scarborough combines the intimacy of a close-knit campus, the breadth of the liberal arts and the depth and rigour of one of the world's best research universities.

camh
mental health is health

The Centre for Addiction and Mental Health (CAMH) is Canada's largest mental health and addiction teaching hospital, as well as one of the world's leading research centres in the area of addiction and mental health. CAMH combines clinical care, research, education, policy development and health promotion to help transform the lives of people affected by mental health and addiction issues. CAMH is fully affiliated with U of T and is a World Health Organization/Pan-American Health Organization Collaborating Centre in Addiction and Mental Health.

IC/ES Data Discovery Better Health

ICES is an independent, not-for-profit organization that produces knowledge to enhance the effectiveness of health care for Ontarians. Internationally recognized for its innovative use of population-based health data and information, ICES evidence supports health policy development and guides changes to the organization and delivery of health care services.

Forewords

LISA I. IEZZONI, MD, MSC

Professor of Medicine, Harvard Medical School

Health Policy Research Center, Mongan Institute Massachusetts General Hospital

On January 25-26, 2010, the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) hosted an interdisciplinary, invitational workshop just outside Washington, DC, to discuss pregnancy in women with physical disability. Although “most women with physical disabilities have normal fertility and are capable of becoming pregnant,” workshop leaders observed, “very little is known about the course and outcomes of pregnancy among women with disabilities.”[1] The workshop aimed to inform strategies to rigorously investigate this heretofore neglected and multi-faceted issue.

As expected, with its National Institutes of Health (NIH) origins, the workshop started very “medical model.” Speakers examined the clinical risks and outcomes for mothers and infants of common conditions causing physical disability, including spinal cord injury, rheumatoid arthritis, multiple sclerosis, cerebral palsy, and spina bifida, and recognized complexities of rare disabling conditions. Later sessions veered into “social model” terrain. Speakers addressed barriers those of us with physical disability confront daily; nevertheless, to drive public health action and policy change, research would need to validate these concerns. Wide-ranging problems included the lack of height adjustable exam tables and roll-on weight scales, clinicians’ views of disabled women as asexual or irresponsible for becoming pregnant, inadequate training of health professionals leading sometimes to troubling recommendations (e.g., that disabled people terminate their pregnancies), and barriers to parenting, including negative perceptions from family members, clinicians, and society. Additional speakers tackled what are now called social determinants or drivers of health, including poverty, transportation problems, inadequate personal assistance services, domestic violence, food insecurity, and inadequate health insurance.[1]

Over several decades, I have attended countless conferences in nondescript, greater Washington, DC, hotel meeting rooms, and barely remember the topics. However, that NICHD meeting, on cold and cloudy January days, stands out. Workshop participants felt energized, poised to do something new and critically important. Ultimately, they reasoned, research could improve health and quality of life for millions of pregnant women with disabilities and their infants, finally giving voice to a largely invisible and often stigmatized group. Despite its narrow focus on physical disability, this effort represented a crucial start. And afterward, with wonderful interdisciplinary colleagues, I raced to submit a proposal on pregnancy and women with physical disability for the next grant deadline, June 2010, before NICHD even posted its first funding opportunity announcement on this topic. What a joy that mixed methods project was – a true privilege to hear from and tell the stories of women, mostly wheelchair users, about their pregnancies and perinatal experiences!

That January 2010 workshop left a long and productive legacy. Since then, NICHD has funded multiple studies of the perinatal experiences of disabled people, including this project. The research reported here adds to the growing body of evidence of disparities in perinatal care and outcomes across diverse disabilities – and is troublingly similar to our findings from more than a decade ago in the U.S. An important strength of this report is considering both medical and social outcomes of pregnancy across diverse disabilities. The report’s thoughtful and evidence-based recommendations provide an excellent guide for improving the quality and accessibility of perinatal care in Ontario, as must happen globally. Following the roadmap offered here can finally shatter barriers to high quality perinatal care for disabled people in Ontario.

---

[1] Signore C, Spong CY, Krotoski D, Shinowara NL, Blackwell, Sean C. Pregnancy in women with physical disabilities. *Obstet Gynecol.* 2011;117:935-47.

Forewords

GWYNNYTH LLEWELLYN, PHD

Professor Emerita, Centre for Disability Research and Policy, Faculty of Medicine and Health, The University of Sydney

Honorary Professorial Fellow, Melbourne School of Population and Global Health, University of Melbourne

The Disability and Pregnancy Study at the centre of this benchmark Report sets a new international standard for conducting multi-perspective, mixed-methods research about pregnancy in people with disabilities.

Many features stand out. The multidisciplinary study team bringing diverse perspectives and critically, the views of people with lived experience of disability to inform the research design, findings and recommendations. The comprehensiveness of the issues addressed prior to, during, and after pregnancy. The thoughtfulness with which the team selected indicators for these issues accounting for data opportunities and limitations. The attention paid to inequities for people with disabilities, noting the less-than-ideal use of diagnosis for this purpose due to the absence of data on functioning, activity limitations and participation restrictions in health administrative data. The study design based on best practice epidemiological methods complemented by stakeholder interviews and an advisory committee to bring real-world experience to thinking through “why are things the way they are, and how can we do better?”.

Ontario is well-served by this Report to guide initiatives to ensure equity and inclusion in pregnancy care for people with disabilities. The robust recommendations for policy and practice reform derive directly from the findings. These recommendations require, as a matter of urgency, that Ontario decision-makers and service-providers across the spectrum – health, disability, social services, housing, education – work with people with disabilities to institute policies and practices that will better support pregnancy experiences.

This Report records the current inequities experienced by people with disabilities in Ontario. It provides a benchmark for Ontario decision-makers to set targets to achieve equity and inclusion in pregnancy care for this group. The Disability and Pregnancy Cohort provides an opportunity to model the potential impact of policy or practice interventions proposed to reach these targets before these are implemented. Outcomes from changes in policy or practice can then be monitored against the Report findings to determine where progress has occurred, or still needs to be made.

The Report is highly relevant well beyond Ontario. It stands out as an exemplar in methodological approach for population-based studies and clarity of presentation for the expanding scientific and policy literature on pregnancy for people with disabilities.

Decision-makers, service-providers and advocates will appreciate the concluding chapter which ‘puts it all together’ in practical terms under four overarching actions. The Report points to several features of health care which contribute to poorer outcomes such as inaccessible pre- and postnatal services and preconception physical and mental health concerns. Other factors such as income, housing, education, employment, discrimination, violence and social exclusion may also play a part. All need to be considered to develop effective service provision.

Researchers will find the detailed Technical Appendix instructive about developing a reasoned and systematic approach to the opportunities and limitations of health administrative datasets. Researchers in Canada and elsewhere, armed with this Report and the technical knowledge within, can advocate for expanding health administrative datasets to be disability inclusive and datasets linked across agencies to examine social determinants and their impact on people with disabilities as parents.

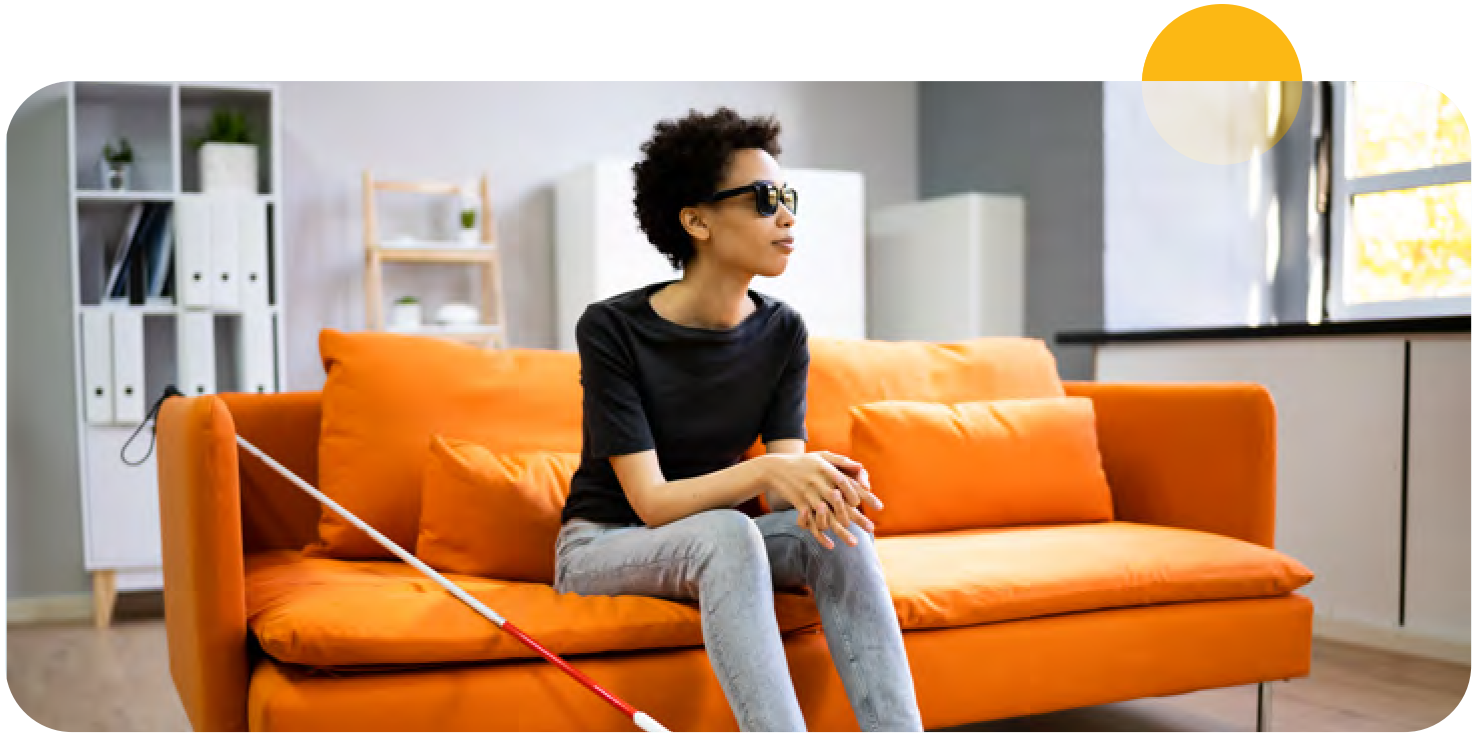
This Report provides evidence-informed policy and practice actions for Canadian decision-makers and service-providers. Readers will look forward to seeing action along the lines recommended and will follow with interest developments in Ontario and across Canada. A further step is to ensure the Report is distributed globally so that others may use it as a model for their district or country in the search for more effective ways to support people with disabilities as they become parents and ultimately, to support the next generation.

00

Executive Summary

The Issue

High-quality pregnancy care is defined by the provision of timely, accessible, respectful, family-centred and evidence-based care across the pregnancy period, from preconception to postpartum and newborn care. Yet, despite policy and clinical efforts, equity and inclusion in high-quality pregnancy care is not guaranteed for all families in Canada. One group consistently reporting unmet pregnancy care needs is people with disabilities.[1]



THE STUDY

“Equity and Inclusion in Pregnancy Care: Report on the Pregnancy Outcomes and Health Care Experiences of People with Disabilities in Ontario” describes the results of the Disability and Pregnancy Study. Funded by the US National Institutes of Health, the Disability and Pregnancy Study was a landmark study that used parallel evidence from health administrative data on nearly 150,000 births to people with disabilities and qualitative interview data from key informants to examine the preconception, pregnancy, labour and birth, and postpartum and newborn health outcomes and health care experiences of people with physical, sensory, developmental and multiple disabilities in Ontario, Canada. This initiative was led by a multidisciplinary team with expertise in epidemiology, qualitative methods, maternal-fetal medicine, paediatrics, psychology, psychiatry and disability, including lived experience of disability, and was further informed by an Advisory Committee of people with disabilities, service-providers and decision-makers. The Disability and Pregnancy Study gathered evidence supporting the need for a more equitable and inclusive approach to pregnancy care that addresses the needs of disabled people.

The goals of this Report are to:

1. **Describe the preconception, pregnancy, labour and birth, and postpartum and newborn health outcomes of people with disabilities in Ontario;**
2. **Highlight the pregnancy care experiences of people with disabilities, from the perspectives of people with disabilities, service-providers and decision-makers; and**
3. **Provide policy and clinical recommendations to improve pregnancy care for people with disabilities.**

---

[1] The language used to refer to disability is critical to ensure individuals’ dignity and respect their preferences. We use person-first and identity-first language to acknowledge the diverse ways in which people prefer to speak about their disability.

KEY FINDINGS

PRECONCEPTION HEALTH AND PREGNANCY RATES

- Sixteen percent of 15 to 49-year-old females[2] in Ontario had a physical, sensory or developmental disability, or multiple disabilities.
- Most females in Ontario experienced adequate preconception health. Even so, there were important disparities between those with and without a disability related to the social determinants of health, physical health, mental health, medication use and experiences of interpersonal violence.
- Females with disabilities had lower pregnancy rates than those without a disability.
- Overall, one in eight pregnancies were to females with a disability.

PREGNANCY OUTCOMES

- Most females in Ontario first received prenatal care within the first trimester and received the recommended number of prenatal care visits. However, females with developmental disabilities tended to have access to prenatal care later and received fewer prenatal care visits than those without disabilities.
- Notably, females with disabilities were more likely than those without a disability to have an emergency department visit or hospital admission during pregnancy.
- Females with disabilities were also more likely to experience rare but serious physical health complications, as well as mental health conditions and interpersonal violence during pregnancy.

LABOUR AND BIRTH OUTCOMES

- Labour induction and Caesarean delivery were more common in females with multiple disabilities than those without a disability.
- Newborns of females with developmental and multiple disabilities were more likely than those of females without a disability to be born preterm, and newborns of females with developmental disabilities were also more likely to be small for their gestational age.
- Females with developmental and multiple disabilities and their newborns had longer birth hospital stays than those without a disability.
- Breastfeeding initiation and support during the birth hospital stay were generally high in all groups, but there were important disparities in these indicators for females with developmental and multiple disabilities.

---

[2] Only information on biological sex, based on individuals' provincial health insurance cards, is available in Ontario health administrative data. This Report uses the language of "females" to describe findings from health administrative data, and gender-inclusive language to describe policy and clinical recommendations.

KEY FINDINGS

POSTPARTUM AND NEWBORN OUTCOMES

- Most females in Ontario received a standard postpartum outpatient visit at six weeks after childbirth.
- However, females with disabilities were more likely than those without a disability to have an emergency department visit or hospital admission in the postpartum period.
- Females with disabilities were also more likely to experience rare but serious physical health complications, as well as mental health conditions and interpersonal violence in the postpartum period.
- Though rare overall, rates of neonatal intensive care unit admission were higher in newborns of females with developmental and multiple disabilities than in newborns of those without disabilities.

PREGNANCY CARE EXPERIENCES

- Interviews with people with disabilities, their service-providers and decision-makers revealed challenges in, and facilitators of, pregnancy care for people with disabilities in Ontario.
- People with disabilities identified many challenges in pregnancy care, including physical and communication accessibility barriers in health care settings; fragmented care across services; poor service-provider knowledge about disability; lack of respect from service-providers; ableist service-provider assumptions about pregnancy and parenting; and inadequate information and decision-making autonomy.
- Facilitators of high-quality pregnancy care identified by people with disabilities included advocacy from individual service-providers, family and friends, and self-advocacy; flexible care strategies, including care delivered at home; and adapted and hands-on help, particularly related to breastfeeding and newborn care.
- Service-providers and decision-makers also identified many challenges in pregnancy care for people with disabilities, including inflexible fee-for-service remuneration policies; inadequate service-provider education and training about disability; and limited resources to support their delivery of care.
- Facilitators of high-quality pregnancy care for people with disabilities identified by service-providers and decision-makers included policy changes to improve access; service-provider advocacy for their patients concerning existing barriers to care; holistic care that addresses both medical and social needs; and tailored care that meets patients' unique needs.

RECOMMENDATIONS

The Disability and Pregnancy Study identified important preconception, pregnancy, labour and birth, and postpartum and newborn health disparities in people with versus without disabilities in Ontario, and significant gaps in the quality of their pregnancy care. Together, these findings signal the need to improve equity and inclusion in pregnancy care for people with disabilities, through the following actions:

1. **Modify health care system structures and processes;**
2. **Increase service-provider knowledge and resources;**
3. **Develop accessible patient supports; and**
4. **Strengthen the scientific evidence base.**

MODIFY HEALTH CARE SYSTEM STRUCTURES AND PROCESSES

The findings of the Disability and Pregnancy Study identified a pregnancy care system that can be fragmented and inaccessible for many people with disabilities. There is a need to modify the structures and processes of pregnancy care so that care is responsive to the needs of all people with disabilities.

We recommend that:

- All pregnancy care spaces, resources and related technology devices should be accessible for the mobility, communication, sensory and learning needs of disabled people.
- Pregnancy care guidelines and physician remuneration policies should be adapted to allow longer pregnancy care visits for people with disabilities, and with greater frequency during critical periods, as needed.
- Person-centred multidisciplinary pregnancy care should be available to people with disabilities, as needed, with systems in place to coordinate such care.
- Pregnancy care should be affirming of people with disabilities.
- Broader health care services for people with disabilities should take a life course perspective that considers their reproductive health needs, including through enhanced preconception care.
- People with disabilities should be engaged in health care system changes through ongoing consultation.

RECOMMENDATIONS

INCREASE HEALTH CARE PROVIDER KNOWLEDGE AND RESOURCES

System-level changes require service-providers who are equipped to deliver high-quality pregnancy care to people with disabilities. However, inadequate service-provider education and training was a significant gap identified in the Disability and Pregnancy Study.

We recommend that:

- All health and social service-providers should receive education and training about disability, disability-related accessibility needs and pregnancy care needs.
- Service-provider education should address ableism and delivery of respectful pregnancy care, including training on the rights of disabled people to dignity, information and bodily and decision-making autonomy.
- Clinical guidelines and other resources that address diverse disabilities and all pregnancy care stages should be developed to support service-providers' delivery of pregnancy care to people with disabilities.
- People with disabilities should be actively involved in the creation of service-provider resources and the delivery of training.

DEVELOP ACCESSIBLE PATIENT SUPPORTS

Actions at the system and service-provider levels should, ultimately, be aimed at improving direct patient supports to reduce health disparities.

We recommend that:

- Evidence-based resources related to disability and pregnancy, including resources for people planning a pregnancy and who are pregnant or postpartum, should be developed to meet patient-identified needs for information.
- Routine pregnancy-related education, including prenatal, breastfeeding and newborn care classes, should be accessible to people with disabilities and address their needs.
- Community organizations should be supported to provide resources to people with disabilities planning a pregnancy, and in pregnancy and postpartum.
- Patient supports should be developed in direct consultation with people with disabilities.

STRENGTHEN THE SCIENTIFIC EVIDENCE BASE

Underlying these efforts is a need to continue to strengthen the scientific evidence base to inform pregnancy care delivery, facilitate evaluation of new initiatives and ultimately hold health care systems accountable for the quality of pregnancy care delivered to people with disabilities.

We recommend that:

- Disability indicators should be routinely included in health administrative data so that pregnancy-related health outcomes for people with disabilities can be monitored at a population level.
- Patient-related outcome and experience measures should be developed in consultation with people with disabilities and used to ensure that efforts to improve pregnancy care meet their needs.
- A national funding strategy should be developed that supports research on disability and health equity, including research on pregnancy-related health disparities in people with disabilities.

Conclusion

Data from the Disability and Pregnancy Study show that many people with disabilities in Ontario experience pregnancy. People with disabilities have a right to high-quality pregnancy care that is timely, accessible, respectful, family-centred and evidence-based. However, our health administrative data showed consistent health disparities for people with disabilities at every stage of the pregnancy journey, and our qualitative interview data identified a pregnancy care system that is inaccessible to many people with disabilities. These findings show that it is time for action, where data can come together with policy and clinical practice leaders as well as people with disabilities, to ensure that pregnancy care is inclusive of and equitable for all people with disabilities.

01

Overview

MAIN MESSAGES

- **High-quality pregnancy care is defined by the provision of timely, accessible, respectful, family-centred and evidence-based care across the pregnancy period.**
- **People with disabilities report unmet pregnancy care needs, despite the United Nations calling for protection of the reproductive rights of people with disabilities, and the World Health Organization and United Nations Population Fund providing guidance for delivery of accessible reproductive health care.**
- **To support provision of pregnancy care that is inclusive of and equitable for all families, there is a need for data to inform clinical guidelines, service-provider education and delivery of care to disabled people.**
- **In the Disability and Pregnancy Study, health administrative data were linked for all 15 to 49-year-old females in Ontario. This gave us data on a cross-section of 532,716 females with disabilities in 2019/20, and longitudinal data on 147,622 births to disabled females from 2010/11 to 2019/20. We used these data to study their preconception, pregnancy, labour and birth and postpartum and newborn health outcomes.**
- **We also conducted in-depth qualitative interviews with 31 people with disabilities and 31 service-providers and decision-makers about the pregnancy care experiences of people with disabilities in Ontario.**
- **The Report is divided into five main chapters. Four chapters cover the preconception, pregnancy, labour and birth and postpartum and newborn health outcomes of people with disabilities, and the fifth chapter describes their pregnancy care experiences broadly. The concluding chapter synthesizes study findings and offers policy and clinical recommendations to improve pregnancy care for people with disabilities.**

Introduction

High-quality pregnancy care is defined by the provision of timely, accessible, respectful, family-centred and evidence-based care across the pregnancy period, from preconception to postpartum and newborn care.[1-3] Yet, the needs of some groups have received less attention in policy and clinical practice, such that pregnancy care does not currently address the needs of *all* families, leading to important issues related to equity and inclusion. One group frequently reporting unmet pregnancy care needs is people with disabilities.

The Disability and Pregnancy Study was a landmark research study that examined the preconception, pregnancy, labour and birth, and postpartum and newborn health outcomes and health care experiences of people with physical, sensory, developmental and multiple disabilities in Ontario, Canada. Funded by the US National Institutes of Health, the initiative was led by a multidisciplinary team with research and clinical expertise in epidemiology, qualitative methods, maternal-fetal medicine, paediatrics, psychology, psychiatry and disability, including lived experience of disability, and was informed by an Advisory Committee comprised of people with disabilities, service-providers and decision-makers. The ultimate goal of the Disability and Pregnancy Study was to provide evidence to support better inclusion of and equity for people with disabilities in pregnancy-related policy and clinical practice, to ensure that pregnancy care in Ontario meets the needs of *all* families.

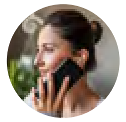
Identity-first and person-first language

The language used to refer to disability is critical to ensure individuals' dignity and respect their preferences. Person-first language focuses on the individual, rather than their disability. Examples include "individuals with disabilities" and "person with paraplegia." This language attempts to dissociate the disability as the defining characteristic of a person and conceptualizes it as one of many characteristics. Person-first language was a response to societal perceptions of disability as dehumanizing and an attempt to emphasize that disability does not "lessen one's personhood."[4] Identity-first language emphasizes one's disability. Examples include "disabled people" and "autistic person." This language validates an individual's identity as a disabled person, rather than suppressing their disability as something negative. Identity-first language allows disabled people to reclaim their power and possession of disability as a positive social identity.[5] In this Report, we use person-first and identity-first language to reflect the diverse ways in which people prefer to speak about their disability.

Gender identity and inclusive language

Some people who experience pregnancy do not identify as cisgender women or use the pronouns "she" or "her." Many sexual and gender minority people encounter difficulties accessing pregnancy care, including feeling accepted and respected.[6] Service-providers often lack training and understanding about sexual and gender minority people's identities, preferred language or pronouns and family configurations. The Society of Obstetricians and Gynaecologists of Canada[7] and the Canadian Association of Midwives[8] are increasingly promoting use of gender-inclusive language, for example, "they" and "parental," rather than "she" and "maternal." Use of gender-inclusive language promotes an environment that acknowledges the way people choose to express their gender. It is an important part of allyship and the promotion of equity and inclusion in pregnancy care. It also benefits all individuals, regardless of gender identity, who may not want to be identified by their gender due to gender-based discrimination.[9] In health administrative data in Ontario, we only have information on biological sex, based on individuals' provincial health insurance cards.

In this Report, we therefore use the language of "females" to describe the specific findings from Ontario health administrative data, and gender-inclusive language to describe policy and clinical recommendations from our work.



HISTORICAL CONTEXT FOR THE REPORT

HISTORY OF EUGENICS

This Report is about the present-day pregnancy-related health outcomes and health care experiences of people with disabilities in Ontario. However, we cannot examine these current issues without acknowledging the long history of eugenic practices that disabled people endured throughout much of the 20th century.

Eugenic practices were common in Canada in the 20th century,[10] and included efforts aimed at "improving" the population through controlled reproduction, such as discouraging procreation of individuals deemed to have "undesirable" characteristics and genetic traits.[10] Alberta and British Columbia instituted sexual sterilization acts in the 1920s and 1930s that allowed involuntary sterilization of people with disabilities at the recommendation of "Eugenics Boards." These acts also protected the surgeons performing sterilization from civil action.[11-13] While Ontario never had formal sterilization laws, the Eugenics Society of Canada, which organized sterilization laws in other provinces, was founded in Ontario.[10] Nationally, eugenic practices had considerable support from the medical community, including the Canadian Medical Association.[10]

Alberta and British Columbia repealed their sterilization acts in the 1970s. However, there continue to be examples of "new eugenics" today, including genome editing and screening of fetuses for disabilities.[14]

Eugenic notions also continue to be seen in ableist societal attitudes toward disability, sexuality, pregnancy and parenting, significantly impacting individuals' health care access and experiences. Across the life course, health care for people with disabilities tends to overlook their reproductive health care needs: people with disabilities are less likely than their peers without disabilities to receive sexual health education, have lower rates of reproductive cancer screening, and have access to a narrower range of contraception options.[14] Pregnant people with disabilities report experiencing significant pressure from service-providers and family members to have an abortion.[15] Parents with disabilities are also more likely than non-disabled parents to experience child welfare involvement and custody loss, even in the absence of evidence of neglect or abuse.[16,17]

It is critical to understand this context when reading about the pregnancy-related health outcomes and health care experiences of people with disabilities described in this Report, since historical eugenic practices and present-day ableism continue to significantly influence the interactions between people with disabilities and their health care providers, as well as the ways in which health care policy and related research activities are prioritized and conceptualized.

Ableism

Ableism describes a system of discrimination and prejudice that excludes people with disabilities, viewing them as "inferior" to people without disabilities.[18] Ableism is rooted in socially constructed ideals of "normalcy" that see disability as something needing to be prevented or corrected.[18] Ableism operates at structural, institutional, interpersonal and internalized levels. Particularly relevant to this Report, ableist notions served as the foundation for eugenic ideologies and practices in the 20th century and continue to be seen in examples of discrimination regarding sexuality, pregnancy and parenting experienced by many disabled people today.[14]

HISTORICAL CONTEXT FOR THE REPORT

RELEVANT POLICY STANDARDS

Major international developments have started to change the landscape of reproductive rights for people with disabilities.[19] In 2006, the United Nations adopted the Convention on the Rights of Persons with Disabilities, the first international treaty on disability.[20] The Convention promotes the view that people with disabilities are active members of society who have the same rights as non-disabled people and are capable of exercising those rights and making their own decisions. Relevant to pregnancy, the Convention ensures the rights of disabled people to:

- Retain their fertility;
- Have access to family planning education;
- Marry and found a family; and
- Decide freely and responsibly on the number and spacing of their children.

Further, the Convention states that people with disabilities have the right to equal access to health services, including quality and affordable health care and programs related to sexual and reproductive health, and that barriers to accessibility in medical facilities should be identified and eliminated.

Canada ratified the Convention in 2010.[21] This legally obligates Canada to ensure that federal and provincial laws, policies and programs aim to improve the social and economic conditions of Canadians with disabilities while ensuring that they have equal rights in the public spheres of health, education, housing and employment.

In 2009, the World Health Organization, in partnership with the United Nations Population Fund, developed a guidance note to support implementation of the Convention in the context of ensuring equitable access to and full inclusion in sexual and reproductive health care for people with disabilities.[22]

The guidance note provides five key recommendations that must be implemented to make such care accessible for disabled people:

1. **Policies and services should be developed in partnership with people with disabilities;**
2. **Stakeholders should increase accessibility of services within their organizations rather than creating “separate or parallel” services;**
3. **Programs should ensure they reach and serve people with disabilities;**
4. **Laws, policies and budgets should reflect the needs of disabled people; and**
5. **Research should be conducted to develop a strong evidence base to improve programs and services.[22]**

While these documents set the standard for delivery of equitable, inclusive reproductive health care, including pregnancy care, few Canadian studies have been performed to provide an evidence base to support the creation of health care policies, service-provider education, clinical guidelines and services for people with disabilities that may be used to implement these standards. This Report addresses this need for data.

HISTORICAL CONTEXT FOR THE REPORT

RELEVANT CANADIAN INITIATIVES

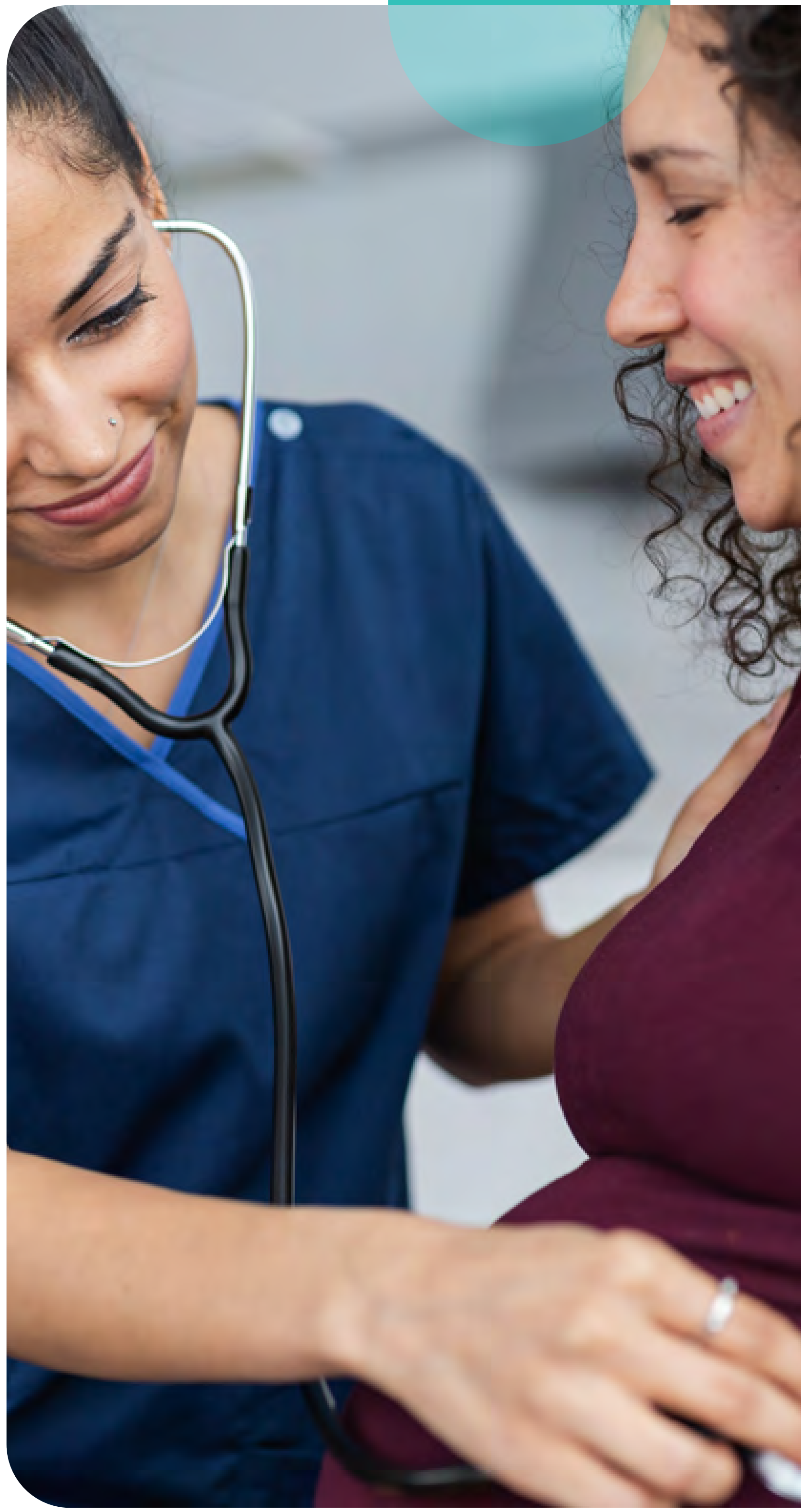
Despite United Nations and World Health Organization recommendations, Canadian health care providers have few clinical guidelines to inform pregnancy care for people with disabilities. In 2020, the Society of Obstetricians and Gynaecologists of Canada published Guideline No. 416: "Labour, Delivery, and Postpartum Care for People with Physical Disabilities,"[23] which focuses on pregnancy care for people with physical disabilities. The only other clinical guidelines in Canada that mention pregnancy care for people with disabilities are the 2018 Canadian Consensus Guidelines for Primary Care of Adults with Intellectual and Developmental Disabilities,[24] which include one guideline about the provision of health care to pregnant people with developmental disabilities.

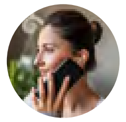
Similarly, there are few examples of accessible pregnancy care services for people with disabilities, but there have been some important developments. In 2017, Sunnybrook Health Sciences Centre in Toronto launched the Accessible Pregnancy Care Clinic – the first of its kind in North America.[25] The goal of this clinic is to improve pregnancy care for people with physical disabilities. Patients receive pregnancy care from a maternal-fetal medicine specialist and an advanced practice nurse and have access to a specially trained sonography team; medical specialists such as neurologists, rheumatologists and physiatrists; and allied health professionals such as physiotherapists, occupational therapists and social workers. The clinic has physically accessible clinic space and birthing suites, and mobility aids such as wheelchair-accessible scales and Hoyer lifts.

A handful of other similar clinics exist in other provinces. In British Columbia, the Advanced Collaborative Care Planning Program at BC Women's Hospital and Health Centre provides specialized pregnancy care to people with spinal cord injuries and other chronic conditions, and the Mary Pack Arthritis Centre has a Pregnancy and Rheumatic Diseases Clinic that provides pregnancy counselling to people with rheumatic diseases.

However, these clinics are the exception rather than the rule and focus only on physical disabilities.Health policy more broadly in Ontario is also insufficient for meeting the needs of people with disabilities. For example, the 2005 Accessibility for Ontarians with Disabilities Act was intended to create and enforce accessibility standards that public, private and non-profit organizations must follow. However, a 2023 report on the implementation of the Act noted that Ontario is unlikely to meet its goal of accessibility for Ontarians with disabilities by 2025,[26] and although a set of health care standards has been proposed by a Standards Development Committee, they are still currently being considered by government.[27]

Service-providers in Ontario therefore have few resources to guide pregnancy care for people with disabilities, and people with disabilities are faced with a health care system that does not prioritize accessibility.





DATA ON DISABILITY AND PREGNANCY IN CANADA

After Canada ratified the United Nations Convention on the Rights of Persons with Disabilities, Employment and Social Development Canada created the New Disability Data Strategy in line with Article 31 of the Convention, which relates to data collection.[28] The main data collection tool related to this strategy is the Canadian Survey on Disability,[28] which provides detailed sociodemographic data on people with disabilities in Canada.[29] Disability-related questions are also typically captured in the Canadian Community Health Survey,[30] an annual, nation-wide survey used to track health status and determinants of health. However, neither survey contains detailed items on pregnancy. Likewise, Canadian surveys that do focus on pregnant people, such as the Maternity Experiences Survey,[31] contain no questions on disability. There have been only a handful of small surveys of the pregnancy experiences of disabled people in Canada.[32,33] There is thus a critical data gap on disability and pregnancy.

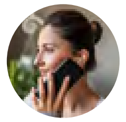
THE DISABILITY AND PREGNANCY STUDY

To address this need for data, we undertook the Disability and Pregnancy Study. The study was led by researchers at the University of Toronto Scarborough and the Centre for Addiction and Mental Health and informed by an Advisory Committee of people with disabilities, service-providers and decision-makers. The focus of this Report is on a cohort of births to disabled people in Ontario, with population-level findings on pregnancy-related health outcomes contextualized by in-depth qualitative interviews with people with disabilities, service-providers and decision-makers about the pregnancy care experiences of people with disabilities in Ontario. We combined the lessons learned from the health administrative data with the rich information provided by these interviews. We then worked with our Advisory Committee to develop a set of recommendations for improving equity and inclusion in pregnancy care for people with disabilities.

CREATING THE DISABILITY AND PREGNANCY COHORT

The first step in this study was creating the Disability and Pregnancy Cohort. Determining who has a disability in Ontario is complex. Beyond surveys, health administrative data offer a way of identifying disability based on diagnoses. Health administrative data describe province-wide datasets containing information on all visits with a physician, emergency department visits and hospital admissions. These datasets are available through ICES and can be linked for individuals using a unique encoded identifier that protects their identities. The datasets date back to 1988 and contain a person's medical record for as long as they received health care in Ontario. These datasets therefore allow us to see all conditions a person was diagnosed with, or sought treatment for, during that time. We can leverage these data to identify people with diagnoses that might be indicative of a disability.

This way of identifying disability is imperfect because it defines disability based on diagnosed "impairments" rather than by asking people about activity limitations or participation restrictions due to environmental or social barriers. However, in the absence of surveys that have questions on self-reported disability and pregnancy, this is the best way we have of conducting population-based research on disability and pregnancy. Health administrative data have the advantage of including people who are often excluded from surveys, including those with developmental disabilities. We hope our study will serve as evidence of the need to include disability questions in pregnancy surveys, pregnancy questions in disability surveys, and self-reported disability status in health administrative data, so that population-level questions about disability and pregnancy can be more easily answered in the future.



THE DISABILITY AND PREGNANCY STUDY

Conceptual models of disability

There are multiple conceptualizations of disability. The medical model views disability as a medical "problem," rather than acknowledging the environmental and social processes that create disability.[34] The medical model focuses on the prevention and/or treatment of disability as a health outcome.[35] It is widely criticized for viewing disability as "pathological."[35] Several other models have been created in response to this criticism. For example, the social model argues that disability is independent of health. It is a construct that is a result of environmental and social factors that limit participation of people with disabilities in society.[34,35] While the social model acknowledges people with disabilities may experience disparities in health and mortality, these disparities are conceptualized as being driven by structural barriers.[34] The disability justice model further acknowledges the ableist structures that we live in, arguing that disability is socially constructed.[36] It centres the inclusion of people most impacted by systems of oppression, including those experiencing intersecting forms of oppression such as ableism and racism and/or heterosexism. Although we are unable to measure many of these social and structural factors in health administrative data, we emphasize, in the interpretation of our findings in this Report, the social and structural factors that might drive identified disparities in pregnancy-related health outcomes and health care experiences as points for intervention in policy and clinical practice.

One of the first steps in creating the Disability and Pregnancy Cohort was to develop a list of diagnoses that may indicate a disability. Our team had already created a list of diagnoses to identify developmental disabilities.[37] We therefore conducted a review to look for studies that developed lists of diagnoses to identify physical and sensory disabilities in health administrative data.[38] We focused on studies identifying diagnoses likely to result in activity limitations and participation restrictions. We then asked 13 health care providers with disability expertise to provide input. Our final list of physical disabilities included congenital anomalies like spina bifida, musculoskeletal disorders like rheumatoid arthritis, neurological disorders like multiple sclerosis, and permanent injuries like spinal cord injuries. Sensory disabilities included hearing and vision loss. Developmental disabilities included autism spectrum disorder, intellectual disability, chromosomal anomalies like Down syndrome, and fetal alcohol spectrum disorder.

People with these diagnoses may vary in the extent to which they find them disabling; some people do not have a diagnosis; and some diagnoses are not recorded if people had trouble accessing care or their provider did not think their diagnosis was relevant to the health care encounter.[38] Nevertheless, our methods give us an idea of the number of people in Ontario with a potentially disabling condition.

The next step in creating the Disability and Pregnancy Cohort was to apply this list of diagnoses to our health administrative datasets. As in prior research,[37] we considered a person to have a disability if they had two or more physician visits, or one or more emergency department visits or hospital admissions for a disability-related diagnosis between the start of the ICES datasets (1988) and the start of the cohort.

THE DISABILITY AND PREGNANCY STUDY

The final step was identifying the health outcomes. For preconception health outcomes, we measured social determinants of health, physical health, mental health, medication use and experiences of interpersonal violence, as well as pregnancy rates in all females of reproductive age in 2019/20. For the other health outcomes, we identified singleton births from 2010/11 to 2019/20. Births were captured by identifying health records of people giving birth in a hospital (98% of births).[39] We then looked at health care records in pregnancy to measure pregnancy outcomes; from birth hospital admissions to measure labour and birth outcomes; within 365 days of childbirth to measure postpartum outcomes; and within 28 days of birth to measure newborn outcomes.

The chapters that follow describe these outcomes. The cross-section of 532,716 reproductive-aged females with physical, sensory and/or developmental disabilities in 2019/20, and the longitudinal cohort of 147,622 births to females with disabilities between 2010/11 and 2019/20, are the largest available nationally and are a rich source of data about a group of people whose pregnancy-related health outcomes have not been sufficiently studied.

Statistical and clinical significance
Throughout this Report, we refer to specific outcomes as being "different" between people with and without disabilities. These statements are made based on an indicator called a "standardized difference," which analyzes how large a difference is between two groups.[40] A standardized difference greater than 0.10 is considered clinically meaningful.[40] This does not mean smaller differences are unimportant. Rather, standardized differences give us an objective threshold for identifying disparities. We provide the percentages of people who experience each outcome, so that actual differences between groups can also be interpreted.

THE DISABILITY AND PREGNANCY STUDY

EXPERIENCES OF PEOPLE WITH DISABILITIES, SERVICE-PROVIDERS AND DECISION-MAKERS

Health administrative data tell us about population-level disparities, i.e., differences in health outcomes between groups that reflect inequities. However, they do not tell us why these disparities exist, or what we should do to address them. Therefore, in undertaking the Disability and Pregnancy Study, it was important to centre our population-level findings in the experiences of people with disabilities, service-providers and decision-makers.

We therefore conducted in-depth, qualitative interviews with 31 people with disabilities and 31 service-providers and decision-makers. These interviews gave us more nuanced information about disabled individuals' pregnancy care experiences and the perceptions of those who deliver, organize or administer such care. These informants were recruited through organizations that serve people with disabilities or parents, the research team's networks and our Advisory Committee. A postdoctoral fellow and two peer researchers with disabilities conducted the interviews in 2019 and 2020. Interviews with people with disabilities followed the chronology of their most recent pregnancy. They were asked about pregnancy planning, and care during pregnancy, labour and birth, and the postpartum period, including the types of services and supports they accessed, if they found these to be helpful, and what they would recommend to improve pregnancy care for disabled people. Interviews with service-providers and decision-makers asked about their disability-related training, the types of pregnancy-related services and supports that are most helpful to people with disabilities, the strengths and gaps in pregnancy care for people with disabilities, and what they would recommend to improve pregnancy care for disabled people.

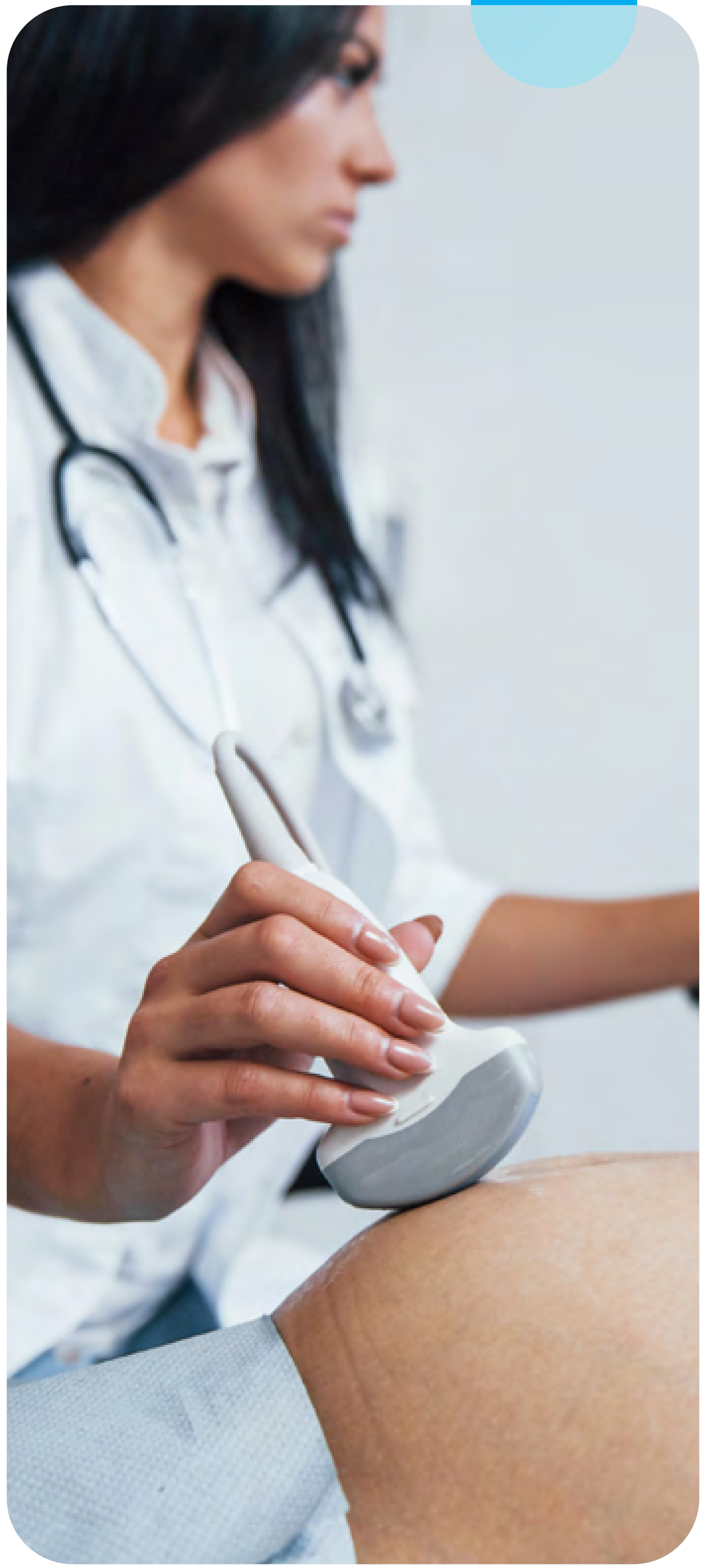
Quotes from these interviews are included in the description of our recommendations related to each chapter. We also include a chapter on the unifying themes about pregnancy care experiences of people with disabilities.

The peer researcher model
Peer researchers are individuals with lived experience of disability who are central members of the research team. Inclusion of peer researchers is critical for valuing community expertise and resisting extractive models of research.[41] In the Disability and Pregnancy Study, peer researchers with disabilities co-led the qualitative interviews and contributed to the recommendations and resources developed from the study as a whole.

REPORT OBJECTIVES

The specific objectives of "Equity and inclusion in pregnancy care: report on the pregnancy outcomes and health care experiences of people with disabilities in Ontario" are to:

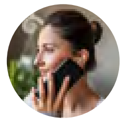
1. **Describe the preconception, pregnancy, labour and birth, and postpartum and newborn health outcomes of people with disabilities in Ontario;**
2. **Highlight the pregnancy care experiences of people with disabilities, from the perspectives of people with disabilities, service-providers and decision-makers; and**
3. **Provide policy and clinical recommendations to improve pregnancy care for people with disabilities.**



REPORT CONTENTS

The Report is divided into five main chapters, along with this background chapter and a concluding chapter.

- Four of the main chapters are focused on a different aspect of the pregnancy period: preconception, pregnancy, labour and birth, and the postpartum and newborn period. These chapters are centred on data exhibits and findings from population-level data, and each concludes with a section on data needs, future research and recommendations, the latter supported with quotes from our qualitative interviews.
- The fifth main chapter identifies unifying themes about pregnancy care experiences from the key informant groups we interviewed.
- The concluding chapter synthesizes findings and makes recommendations for policy and clinical practice to improve pregnancy care for disabled people.
- Main messages are listed on the first page of each chapter. We define technical terms in boxes where they are first used, and a technical appendix at the end of the Report provides methodological details.
- Many of the findings referenced in this Report are published in greater detail in academic journals; references to these published papers are given at the end of each chapter.
- Finally, we provide a list of promising practices and resources at the end of the Report that may serve as examples to support the implementation of our recommendations.



REPORT CONTENTS

CHAPTER 2: PRECONCEPTION HEALTH AND PREGNANCY RATES

Preconception health describes the health of all individuals of reproductive age. The first prenatal care visit is often too late to address important preconception risk factors that affect pregnancy outcomes, so the World Health Organization recommends all reproductive-aged people receive support to promote their preconception health. Chapter 2 provides data to inform the development of preconception care for people with disabilities, including the frequency of disability in reproductive-aged females, the preconception health characteristics of females with and without disabilities, and pregnancy rates in females with and without disabilities.

CHAPTER 3: PREGNANCY OUTCOMES

Access to prenatal care reduces risks of complications in pregnancy. Late or infrequent prenatal care and hospital care signal that more could be done to connect pregnant patients with outpatient care. Likewise, measures of physical health, mental health and other needs of pregnant people are critical for informing the content and structure of prenatal care. Chapter 3 provides data to inform high-quality prenatal care for people with disabilities, including indicators of prenatal outpatient care access, emergency department visits and hospital admissions, and physical health, mental health and interpersonal violence, in pregnancy in females with and without disabilities.

CHAPTER 4: LABOUR AND BIRTH OUTCOMES

Labour and birth are a major transition in a person's life, with care in this period critical for creating a positive experience. Labour and delivery interventions like Caesarean delivery and birth outcomes like preterm birth indicate the need for extra support after childbirth. Other broad factors, like breastfeeding initiation and support during the birth hospital stay, are important indicators of hospital supports. Chapter 4 provides data to inform labour and birth care of people with disabilities, including indicators of labour and delivery interventions, birth outcomes, length of hospital stay, and breastfeeding initiation and support, in females with and without disabilities.

CHAPTER 5: POSTPARTUM AND NEWBORN OUTCOMES

The postpartum period is a time of significant physiological and psychological change. Late or missed postpartum care visits and hospital care show the need for better access to outpatient care; and measures of physical health, mental health and other needs, including newborn health care needs, are critical for informing the content and structure of postpartum care. Chapter 5 provides data to inform postpartum care for people with disabilities, including indicators of postpartum outpatient care access, emergency department visits and hospital admissions, and physical health, mental health and experiences of interpersonal violence in females with and without disabilities in the postpartum period, and health care needs of their newborns.

REPORT CONTENTS

CHAPTER 6: PREGNANCY CARE EXPERIENCES: UNIFYING THEMES

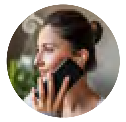
Provision of high-quality pregnancy care to people with disabilities in Ontario requires an understanding of the pregnancy care experiences of people with disabilities. Chapter 6 provides a summary of unifying themes from in-depth qualitative interviews with people with disabilities, service-providers and decision-makers on the challenges in, and facilitators of, high-quality pregnancy care for people with disabilities to inform the development of pregnancy care that is truly equitable and inclusive.

CHAPTER 7: EQUITY AND INCLUSION IN PREGNANCY CARE: CONCLUSION

The final chapter synthesizes the findings from each chapter and proposes actions related to modifying health care system structures and processes, increasing service-provider knowledge and resources, developing accessible patient supports, and strengthening the scientific evidence base. It is through these changes that pregnancy care in Canada can be equitable for and inclusive of all families.

Related publications

- **Brown HK, Carty A, Havercamp S, Parish S, Lunsky Y. Algorithms to identify reproductive-aged women with physical and sensory disabilities in administrative health data: a systematic review. *Disabil Health J* 2020; 13(3):100909.**
- **Proulx L, Brown H, Lunsky Y, Tarasoff L, Welsh K. A call for inclusive health research. Toronto: *Healthy Debate;* 2021.**



RETURN TO PREVIOUS PAGE

References

1. Sword W, Heaman MI, Brooks S, Tough S, Janssen PA, Young D, et al. Women's and care providers' perspectives of quality prenatal care: a qualitative descriptive study. *BMC Preg Childbirth* 2012; 12:29.
2. Rush J. *Family-Centred Maternity Care Scoring Tool Project: Phase II: Obtaining Parent Input.* Toronto: Ontario Ministry of Health, Institutional Services Branch, Maternal and Newborn Initiatives; 1997.
3. Public Health Agency of Canada. *Family-Centred Maternity and Newborn Care: National Guidelines.* Ottawa: PHAC; 2017.
4. Andrews EE, Powell RM, Ayers K. The evolution of disability language: choosing terms to describe disability. *Disabil Health J* 2022; 15(3):101328.
5. Botha M, Hanlon J, Williams GL. Does language matter? Identity-first vs. person-first language use in autism research: a response to Vivanti. *J Autism Dev Disord* 2023; 53:870–8.
6. Besse M, Lampe NM, Mann ES. Experiences with achieving pregnancy and giving birth among transgender men: a narrative literature review. *Yale J Biol Med* 2020; 93(4):517–28.
7. Bonifacio J. *Creating inclusive spaces for the LGBTQ+ community: learning from the experts.* Ottawa: Society of Obstetricians & Gynaecologists of Canada; 2020.
8. Canadian Association of Midwives. *A statement on gender inclusivity & human rights.* Montreal: Canadian Association of Midwives; 2015.
9. Nelson M. *Beyond the binary: what does gender-inclusive women's health research look like?* Vancouver: Women's Health Research Institute; 2022.
10. de Bruin T, Robertson G. Eugenics in Canada. *The Canadian Encyclopedia;* 2019. Accessed November 2, 2022. https://www.thecanadianencyclopedia.ca/en/article/eugenics
11. Province of British Columbia. *An Act Respecting Sexual Sterilization.* Statutes of the Province of British Columbia; N.D. Accessed November 2, 2021. https://www.bclaws.gov.bc.ca/civix/document/id/hstats/hstats/1887728313
12. Grekul J. The right to consent? Eugenics in Alberta, 1928–1972. In: Miron J, editor. *A history of human rights in Canada: essential issues.* Toronto: Canadian Scholars' Press; 2009; p. 135–54.
13. Grekul J, Krahn A, Odynak D. Sterilizing the "feeble-minded": eugenics in Alberta, Canada, 1929–1972. *J Hist Sociol* 2004; 17:358–84.
14. McConnell D, Phelan S. The devolution of eugenic practices: sexual and reproductive health and oppression of people with intellectual disability. *Soc Sci Med* 2022; 298:114877.
15. Björnsdóttir K, Stefánsdóttir Á, Stefánsdóttir GV. People with intellectual disabilities negotiate autonomy, gender and sexuality. *Sex Disabil* 2017; 35(3):295–311.
16. Tøssebro J, Midio T, Paulsen V, Berg B. Prevalence, trends and custody among children of parents with intellectual disabilities in Norway. *J Appl Res Intellect Disabil* 2017; 30(3):533–42.
17. Brown HK, Potvin L, Lunsky Y, Vigod S. Maternal intellectual or developmental disability and newborn discharge to protective services. *Pediatrics* 2018; 142(6):1–12.
18. Powell R. Confronting eugenics means finally confronting its ableist roots. *Race Gender Soc Just* 2021; 27(3):607–33.
19. Galer D. *Working towards equity: disability rights and employment in late twentieth century Canada.* Toronto: University of Toronto Press; 2018.
20. United Nations. *Convention on the Rights of Persons with Disabilities. Treaty Series, 2515, 3.* New York: United Nations General Assembly; 2006.
21. Government of Canada. *Promoting rights of persons with disabilities.* Ottawa: Government of Canada; 2022.
22. World Health Organization and United Nations Population Fund. *Promoting sexual and reproductive health for persons with disabilities – WHO/UNFPA Guidance Note.* Geneva: WHO; 2009.
23. Berndl A, Ladhani N, Wilson RD, Basso M, Jung E, Tarasoff LA, et al. Guideline No. 416: labour, delivery, and postpartum care for people with physical disabilities. *J Obstet Gynaecol Can* 2021; 43(6):769–80.
24. Sullivan WF, Diepstra H, Heng J, Ally S, Bradley E, Casson I, Hennen B, et al. Primary care of adults with intellectual and developmental disabilities: 2018 Canadian consensus guidelines. *Can Fam Physician* 2018; 64(4):254–79.
25. Sunnybrook Health Sciences Centre. *Accessible Care Pregnancy Clinic: about.* Accessed November 2, 2022. https://sunnybrook.ca/content/?page=accessible-care-pregnancy-clinic-about
26. Donovan R. *Independent 4th review of the Accessibility for Ontarians with Disabilities Act (AODA).* Accessed January 9, 2024. https://files.ontario.ca/msaa-fourth-review-of-aoda-final-report-en-2023-06-30.pdf
27. AODA Accessibility. *AODA Healthcare Standards.* Accessed December 5, 2023. https://www.aoda.ca/aoda-healthcare-standards/
28. Cloutier E, Grondin C, Lévesque A. *Canadian Survey on Disability, 2017:* concepts and methods guide. Ottawa: Statistics Canada; 2018.
29. Morris S, Fawcett G, Brisebois L, Hughes J. *A demographic, employment, and income profile of Canadians with disabilities aged 15 years and over, 2017.* Ottawa: Statistics Canada; 2018.
30. Béland Y, Dale V, Dufour J, Hamel M, Coats R. *The Canadian Community Health Survey: building on the success from the past.* Ottawa: Statistics Canada; 2005.
31. Dzakpasu S, Kaczorowski J, Chalmers B, Heaman M, Duggan J, Neusy E. The Canadian Maternity Experiences Survey: design and methods. *J Obstet Gynaecol Can* 2008; 30(3):207–16.

References

32. Cooper N. *Pregnancy and parenting experiences of Canadian women living with physical disabilities (Unpublished master's thesis).* Toronto: University of Toronto; 2006. ProQuest Order No. MR16216.
33. DisAbled Women's Network Canada. *The only parent in the neighbourhood: mothering and women with disabilities.* Montreal: DAWN Canada; 2007.
34. Krahn G, Campbell VA. Evolving views of disability and public health: the roles of advocacy and public health. *Disabil Health J* 2011; 4(1):12–8.
35. Kafer A. *Feminist, queer, crip.* Bloomington and Indianapolis: Indiana University Press; 2013.
36. Sins Invalid. *Skin, tooth, and bone – the basis of movement is our people: a disability justice primer.* San Francisco: Dancer's Group; 2016.
37. Lin E, Balogh R, Cobigo V, Ouellette-Kuntz H, Wilton AS, Lunsky Y. Using administrative health data to identify individuals with intellectual and developmental disabilities: a comparison of algorithms. *J Intellect Disabil Res* 2013; 57(5):462–77.
38. Brown HK, Carty A, Havercamp S, Parish S, Lunsky Y. Algorithms to identify reproductive-aged women with physical and sensory disabilities in administrative health data: a systematic review. *Disabil Health J* 2020; 13(3):100909.
39. Statistics Canada. *Live births and fetal deaths (stillbirths) by place of birth (hospital or non-hospital), Canada, provinces and territories, annual, 2021.* Ottawa: Statistics Canada; 2021. Accessed July 26, 2021. https://www150.statcan.gc.ca/t1/tbl1/en/tv.action?pid=1310042901.
40. Austin PC. Using the standardized difference to compare the prevalence of a binary variable between two groups in observational research. *Comm Stat* 2009; 38:1228–34.
41. Nicolaidis C, Raymaker D, Kapp SK, Baggs A, Ashkenazy E, McDonald K, et al. The AASPIRE practice-based guidelines for the inclusion of autistic adults in research as co-researchers and study participants. *Autism Int J Res Pract* 2019; 23(8):2007–19.

SIOBHAN is a blind woman who lives in a suburban region with her children and husband.

Siobhan sadly lost one of her babies due to a heart defect. This loss substantially shaped her most recent pregnancy experience.

For her previous pregnancies, Siobhan's husband assisted her with taking pregnancy tests by reading the instructions and the results because the tests are sight-dependent. However, in her most recent pregnancy, Siobhan wanted to take the pregnancy test without help, as her husband was also grieving their previous loss: *"I wanted to test without my husband because I was excited to be having another baby, but I didn't know how he was going to feel because it was just a couple of months after we lost the previous one."*

However, it was very difficult for Siobhan to take the test on her own because she was unable to find an accessible pregnancy test: *"There's no blind accessible pregnancy test, which is weird to me… And I feel like it would be easy if you just do; one beep or two beeps or whatever, you could have it say 'pregnant'."*

During her most recent pregnancy, Siobhan was diagnosed with gestational diabetes and had to access a diabetes clinic in a hospital, where she again encountered several accessibility-related barriers. The first time she visited the clinic, she shared how difficult it was to navigate the environment: *"The staff were great, but the standard thing was, 'Okay, go downstairs and get yourself a glucose meter and go home and test' and this and that right? But, I don't know how to find the pharmacy downstairs, I don't know how to get a glucose meter once I'm there. Once I get the glucose meter, I don't know how to read the instructions, I don't know how to test… This is all a new experience to me."*

Despite these challenges, Siobhan found the dietician at the diabetes clinic to be a great help: *"The dietician, she was fantastic, she said I could just email her my results on Excel. So I kept my own tables on Excel and sent it to her and she actually did arrange that we just do phone calls unless I noticed a big problem. We would just do a weekly or biweekly phone call; I didn't actually have to come in every week."* This accommodation was extremely helpful because it meant that Siobhan did not often need to navigate the inaccessible diabetes clinic.

When asked what advice she would give to health care providers to make pregnancy care better for blind people, Siobhan said that *"a short time of teaching pays off."* For example, she said that it would have been helpful if the health care staff at the diabetes clinic took the time to teach her how to test her own glucose levels and do a practice run with her using the sight-dependent test. These simple measures would have made her pregnancy care experience much more accessible.

Based on an interview with a study participant. The name and details have been changed for privacy.

02

Preconception Health and Pregnancy Rates

MAIN MESSAGES

- **Little is known about the preconception health needs of people with disabilities.**
- **We described the frequency of disability in reproductive-aged females in Ontario, and the preconception health characteristics and pregnancy rates of females with and without disabilities.**
- **Among 15 to 49-year-old females in Ontario, 16.3% had a physical, sensory or developmental disability, or multiple disabilities.**
- **Most reproductive-aged females in Ontario experienced adequate preconception health, but there were important disparities between females with and without disabilities related to the social determinants of health, physical health, mental health, medication use and experiences of interpersonal violence.**
- **Pregnancy rates in females with disabilities were lower than in females without disabilities, but, overall, one in eight pregnancies in Ontario were to females with a disability.**
- **Current preconception health care programs should be reviewed to ensure they address the needs of people with disabilities.**

Introduction

Preconception health describes the health of all individuals of reproductive age, regardless of their pregnancy intentions.[1] Preconception health has a strong impact on pregnancy outcomes, including risks of stillbirth, preterm birth and other complications.[2-4] Half of pregnancies in North America are unplanned,[5] and the first prenatal care visit is often too late to address risk factors that affect pregnancy outcomes.[6] Therefore, the World Health Organization recommends all reproductive-aged people receive support to promote preconception health.[1] These supports address social determinants of health such as poverty, and physical health, mental health, medication use and interpersonal violence.[1] There are tailored preconception health resources for people with chronic physical health conditions such as diabetes[7] and HIV.[8] Yet, few such supports exist for people with disabilities.

To inform the development of high-quality preconception health supports for people with disabilities, the main questions this chapter will answer are:

- How common is disability among reproductive-aged females?
- How do the preconception health characteristics of females with disabilities compare to those without disabilities?
- How do the pregnancy rates of females with disabilities compare to those without disabilities?

BACKGROUND

PREVALENCE OF DISABILITY AMONG REPRODUCTIVE-AGED FEMALES

Statistics on the frequency of disability in the reproductive-aged population vary depending on the definition of disability and the data sources used. The Canadian Survey on Disability, for example, reports that 24% of all females have a disability, including 16% of 15 to 24-year-olds and 18% of 25 to 44-year-olds.[9] Similarly, in the United States, the Centers for Disease Control and Prevention report that 24% of all females have a disability, including 12% of 18 to 44-year-old females.[10] As described in Chapter 1, Ontario's population-based data give us the opportunity to understand how many reproductive-aged females in the Province have a recorded disability.

In this chapter, the prevalence of disability among reproductive-aged females is reported as the proportion of all 15 to 49-year-old females in Ontario in 2019/20 with a diagnosis of a physical, sensory and/or developmental disability in their health record. We report the prevalence of disability overall, as well as that of specific physical disabilities (i.e., congenital anomalies, musculoskeletal disorders, neurological disorders and permanent injuries), sensory disabilities (i.e., hearing and vision loss), developmental disabilities (i.e., autism spectrum disorder and other developmental disabilities), and multiple disabilities (i.e., two or more of physical, sensory or developmental disabilities). For more details on how disability was measured, refer to the Technical Appendix.

PRECONCEPTION HEALTH

Most of what we know about the preconception health of disabled people comes from research in the US. Several studies, all using national survey data, showed reproductive-aged females with disabilities were more likely than those without disabilities to experience poverty, chronic physical and mental health conditions, and interpersonal violence, and to smoke cigarettes.[11-13] A strength of using survey data to study this topic is that disability is self-reported. However, as described in Chapter 1, a weakness is that surveys tend to exclude groups who are unable to take part in research because of their disability or other barriers. Health administrative data allow us to look at several preconception health indicators using information for the entire population.

In this chapter, preconception health is measured using indicators available in health administrative data to measure social determinants of health (i.e., neighbourhood-level income, material deprivation and residential instability), physical health (i.e., diabetes mellitus, chronic hypertension and asthma), mental health (i.e., mood and anxiety, psychotic, substance use and other mental disorders, and self-harm), use of teratogenic medications (i.e., that increase risk of birth defects if taken in pregnancy), and history of emergency department visits for interpersonal violence.[1] We report the proportions of 15 to 49-year-old females in Ontario in 2019/20 with physical, sensory, developmental and multiple disabilities, and without disabilities, who had each indicator. For more details on how preconception health indicators were measured, refer to the Technical Appendix.

Preconception health is defined as the health of all individuals of reproductive-age, regardless of their pregnancy intentions, with a focus on factors that can be modified to improve pregnancy outcomes, such as the social determinants of health, physical health, mental health, use of medications that could cause birth defects if taken in pregnancy, and experiences of interpersonal violence.[1]

BACKGROUND

PREGNANCY RATES

Like preconception health, most of what we know about pregnancy rates in people with disabilities comes from national surveys from the US. These surveys show pregnancy rates were fairly similar in people with physical and sensory disabilities compared to those without disabilities, and lower in people with developmental disabilities.[14-16] One study from California used health administrative data to show that the proportion of births to people with a disability increased from 0.3% in 2000 to 0.8% in 2010.[17] However, this study was only able to identify disability status at the time of the birth. In Ontario, linkage of health records across time allows us to identify disability-related diagnoses in all available health records leading up to a birth, better identifying disability.

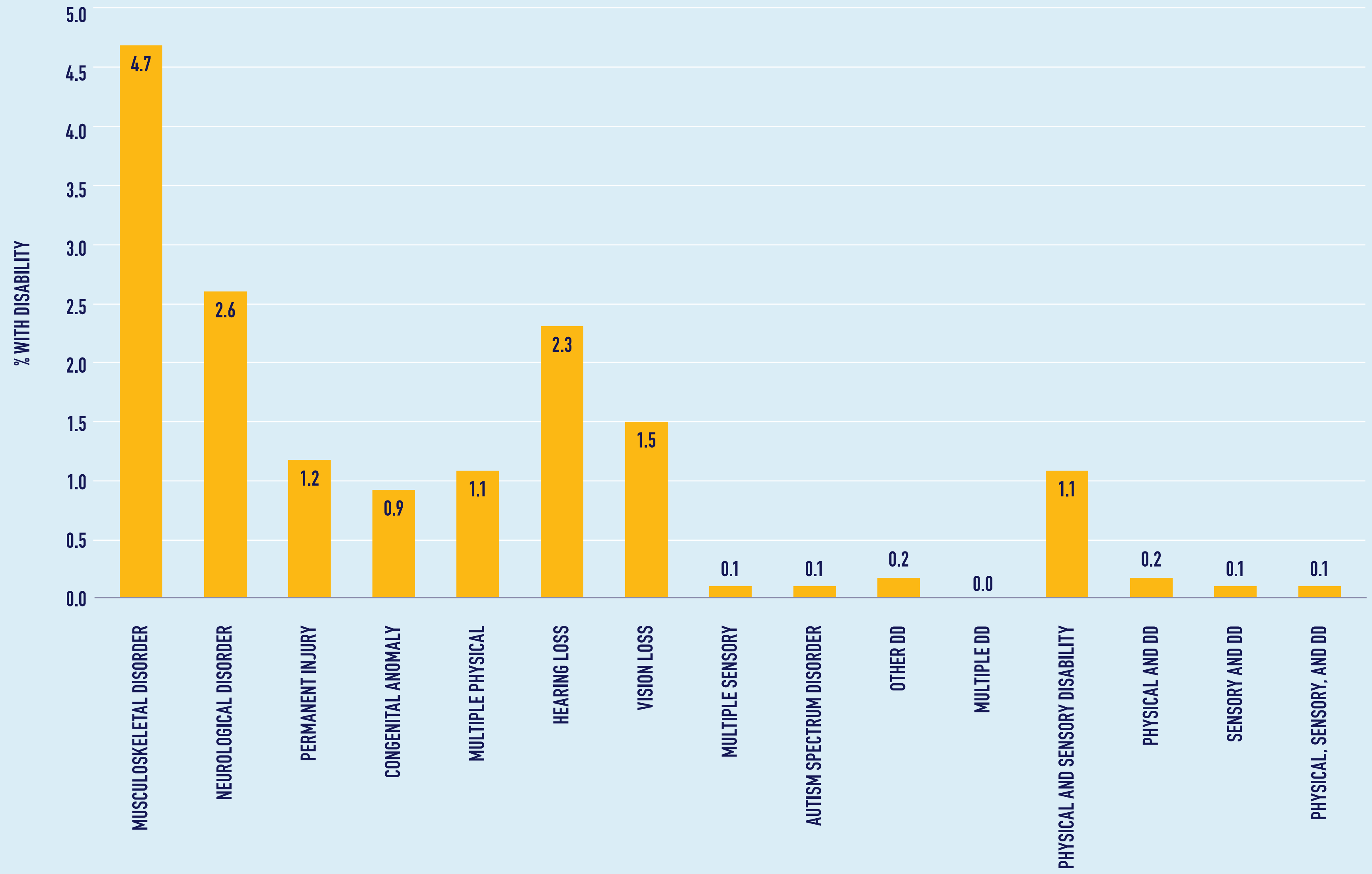
In this chapter, pregnancy is defined as a livebirth, stillbirth, induced abortion or miscarriage recorded in a health care encounter. We report the number of pregnancies per 1,000 15 to 49-year-old females with physical, sensory, developmental and multiple disabilities, and without disabilities, in Ontario in 2019/20. For more details on how pregnancy was identified in health administrative data, refer to the Technical Appendix.

Pregnancy rates are defined as the number of livebirths, stillbirths, induced abortions or miscarriages per 1,000 females aged 15 to 49 years.

EXHIBITS AND FINDINGS

EXHIBIT 2.1

PREVALENCE OF DISABILITY AMONG 15 TO 49-YEAR-OLD FEMALES, IN ONTARIO, 2019/20



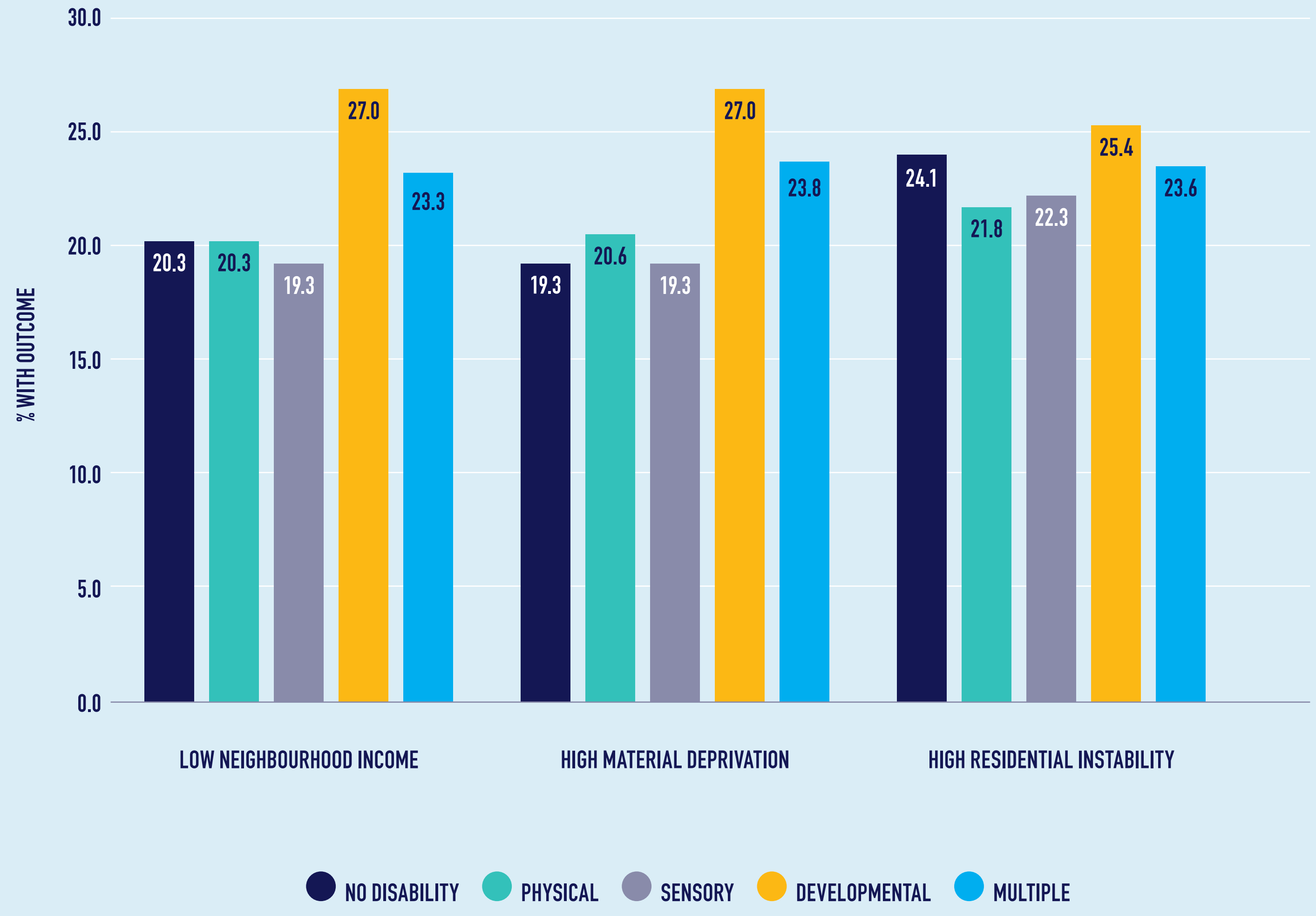
FINDINGS

- Overall, 16.3% of 15 to 49-year-old females in Ontario had a recorded disability.
- The most common disabilities were physical disabilities (10.5%), followed by sensory disabilities (4.0%), multiple disabilities (1.4%) and developmental disabilities (0.4%).
- Among physical disabilities, the most common were musculoskeletal disorders (4.7%), followed by neurological disorders (2.6%), permanent injuries (1.2%) and congenital anomalies (1.1%).
- Among sensory disabilities, the most common was hearing loss (2.3%) followed by vision loss (1.5%).
- Among developmental disabilities, the most common was other developmental disability (0.2%) followed by autism spectrum disorder (0.1%).
- Among multiple disabilities, the most common were physical and sensory (1.1%), followed by physical and developmental (0.2%), sensory and developmental (0.1%) and all three disability types (0.1%).

EXHIBITS AND FINDINGS

EXHIBIT 2.2

PREVALENCE OF SOCIAL DETERMINANTS OF HEALTH AMONG 15 TO 49-YEAR-OLD FEMALES WITH AND WITHOUT DISABILITIES, IN ONTARIO, 2019/20



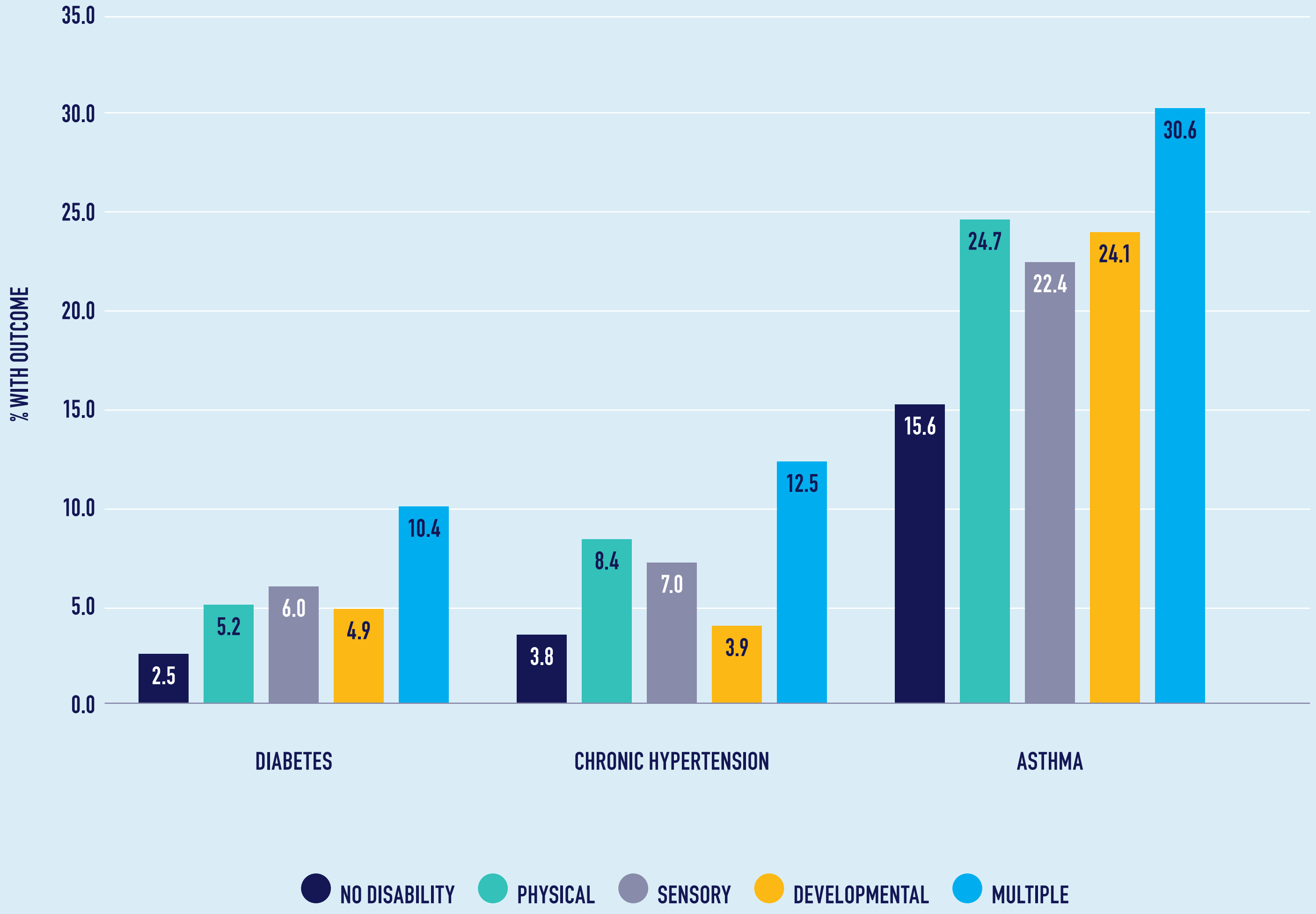
FINDINGS

- Females with developmental disabilities (27.0%) were more likely than those without a disability (20.3%) to live in neighbourhoods with the lowest income quintile.
- Females with developmental (27.0%) and multiple disabilities (23.8%) were more likely than those without a disability (19.3%) to live in neighbourhoods with the highest material deprivation quintile.

EXHIBITS AND FINDINGS

EXHIBIT 2.3

PREVALENCE OF PHYSICAL HEALTH INDICATORS AMONG 15 TO 49-YEAR-OLD FEMALES WITH AND WITHOUT DISABILITIES, IN ONTARIO, 2019/20



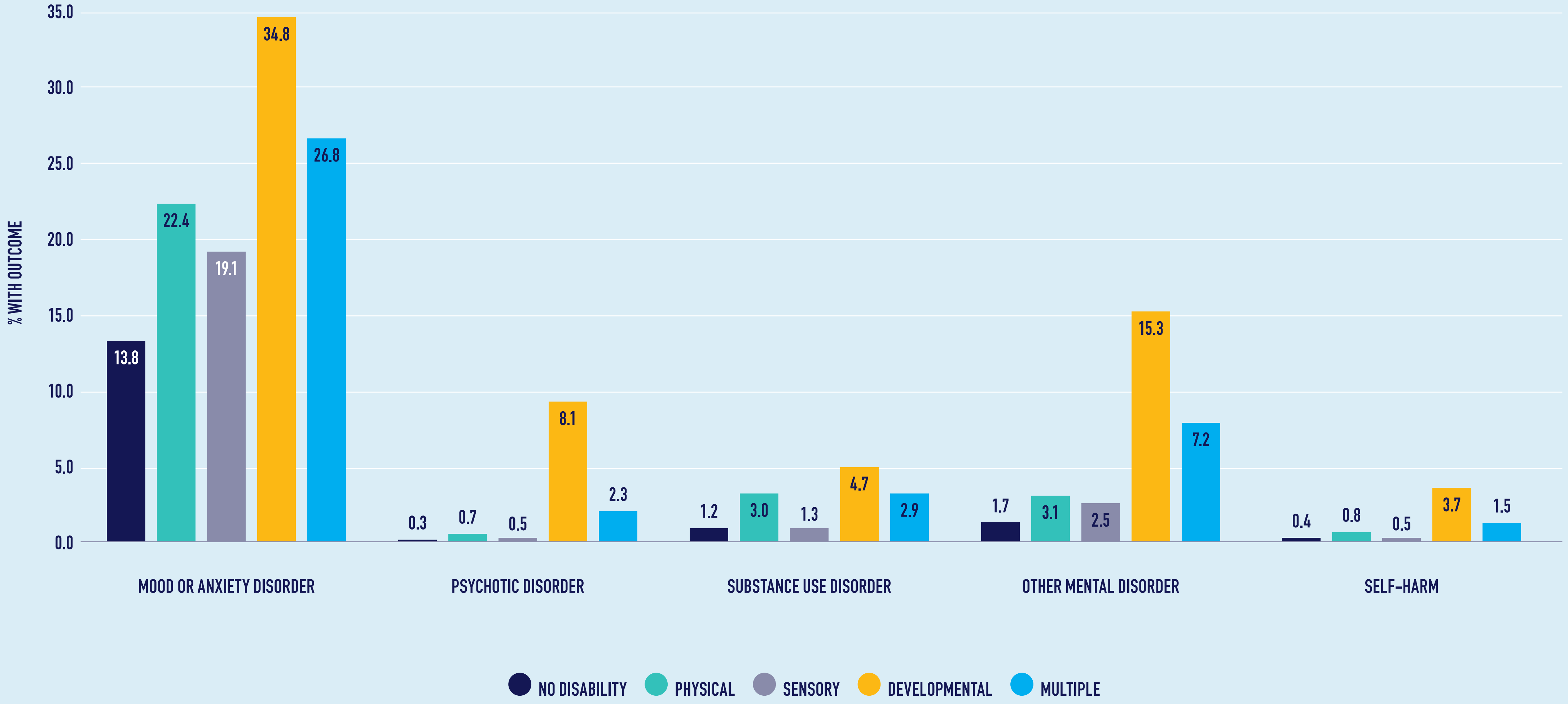
FINDINGS

- Diabetes mellitus was more common in females with physical (5.2%), sensory (6.0%), developmental (4.9%), and multiple disabilities (10.4%) than in those without a disability (2.5%).
- Chronic hypertension was more common in females with physical (8.4%), sensory (7.0%), and multiple disabilities (12.5%) than in those without a disability (3.8%).
- Asthma was more common in females with physical (24.7%), sensory (22.4%), developmental (24.1%), and multiple disabilities (30.6%) than in those without a disability (15.6%).

EXHIBITS AND FINDINGS

EXHIBIT 2.4

PREVALENCE OF MENTAL HEALTH INDICATORS AMONG 15 TO 49-YEAR-OLD FEMALES WITH AND WITHOUT DISABILITIES, IN ONTARIO, 2019/20



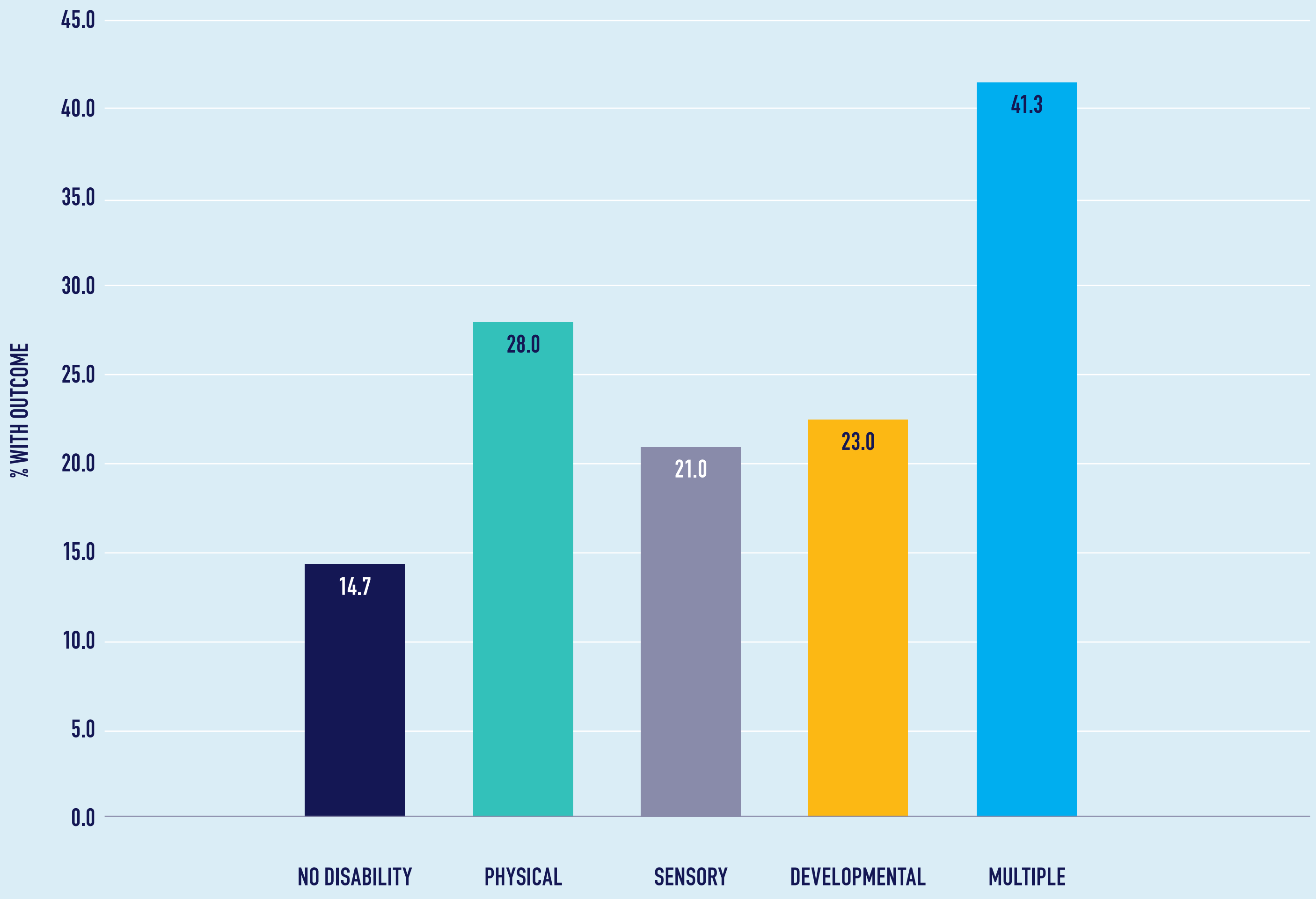
FINDINGS

- Mood and anxiety disorders were more common in females with physical (22.4%), sensory (19.1%), developmental (34.8%) and multiple disabilities (26.8%) than those without a disability (13.8%).
- Psychotic disorders were more common in females with developmental (8.1%) and multiple (2.3%) disabilities than in those without a disability (0.3%).
- Substance use disorders were more common in females with physical (3.0%), developmental (4.7%), and multiple disabilities (2.9%) than in those without a disability (1.2%).
- Other mental disorders were more common in females with developmental (15.3%) and multiple (7.2%) disabilities than in those without a disability (1.7%).
- Self-harm was more common in females with developmental (3.7%) and multiple disabilities (1.5%) than in those without a disability (0.4%).

EXHIBITS AND FINDINGS

EXHIBIT 2.5

PREVALENCE OF TERATOGENIC MEDICATION USE AMONG 15 TO 49-YEAR-OLD FEMALES WITH AND WITHOUT DISABILITIES RECEIVING PUBLICLY FUNDED DRUG BENEFITS, IN ONTARIO, 2019/20



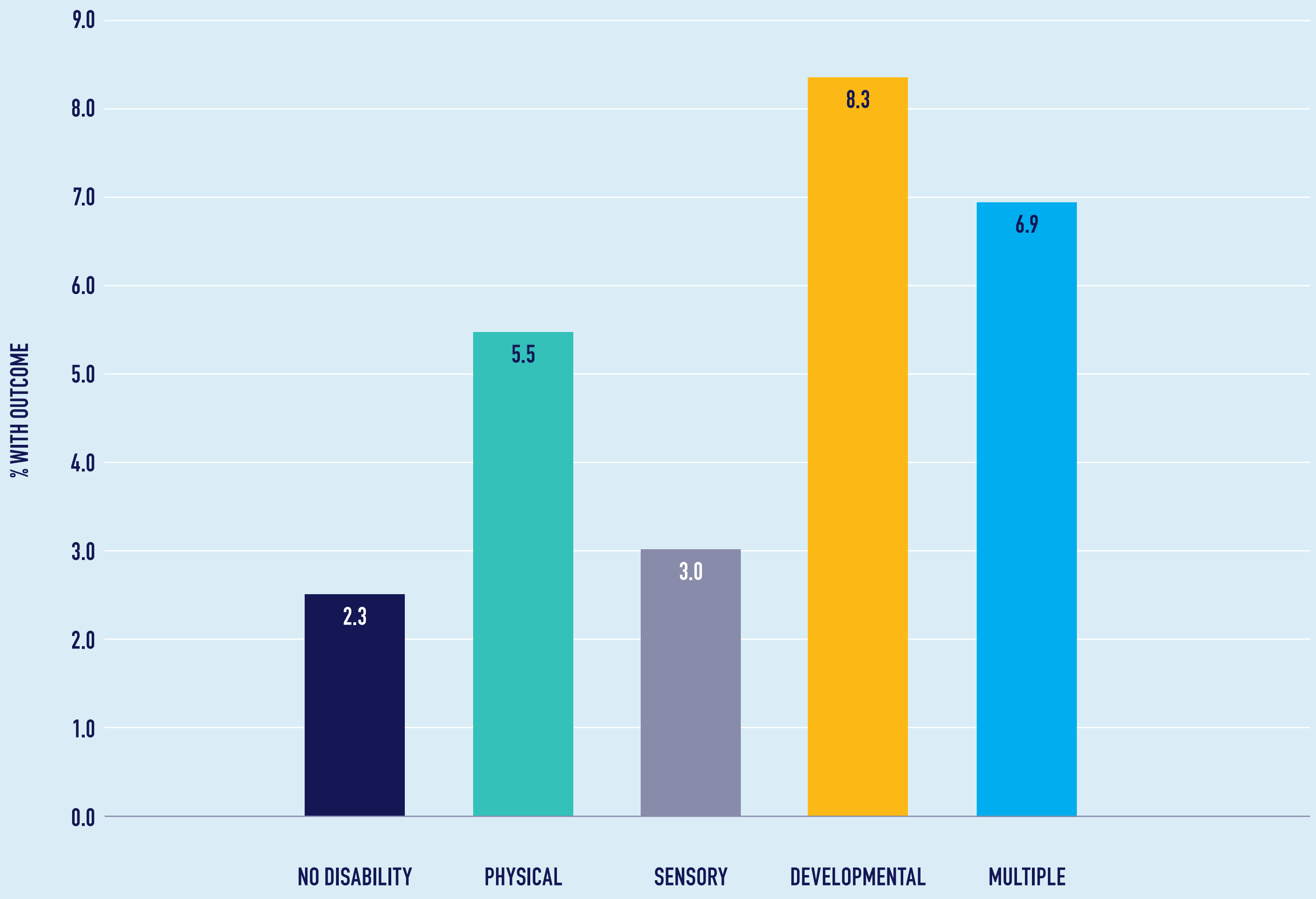
FINDINGS

- Among females receiving publicly funded drug benefits, females with physical (28.0%), sensory (21.0%), developmental (23.0%), and multiple disabilities (41.3%) were more likely than those without a disability (14.7%) to use medications that are associated with an increased risk of birth defects if taken in pregnancy.

EXHIBITS AND FINDINGS

EXHIBIT 2.6

PREVALENCE OF A HISTORY OF INTERPERSONAL VIOLENCE AMONG 15 TO 49-YEAR-OLD FEMALES WITH AND WITHOUT DISABILITIES, IN ONTARIO, 2019/20



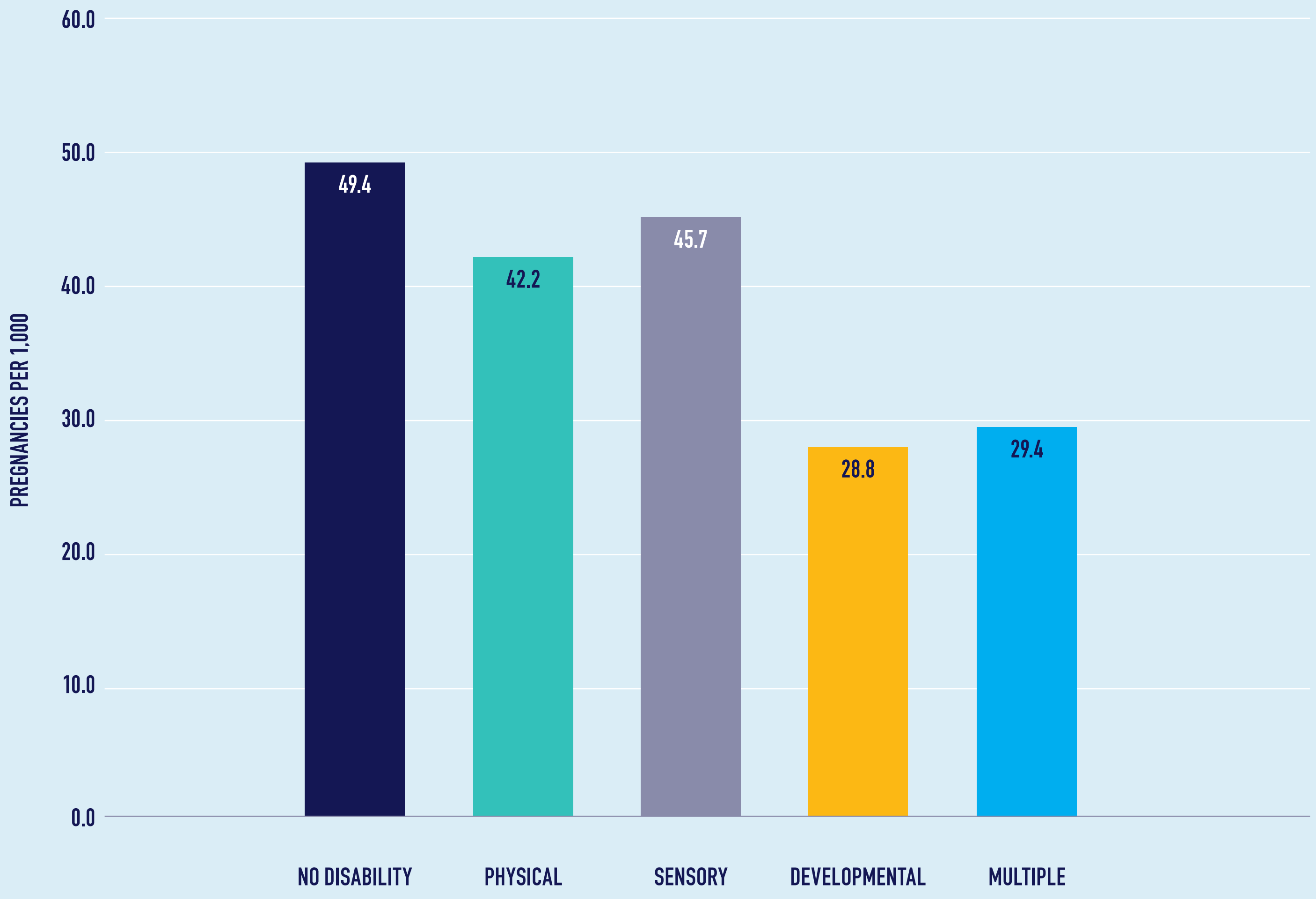
FINDINGS

- Females with physical (5.5%), developmental (8.3%) and multiple disabilities (6.9%) were more likely than those without a disability (2.3%) to have a history of emergency department visits for interpersonal violence.

EXHIBITS AND FINDINGS

EXHIBIT 2.7

PREGNANCY RATE PER 1,000 15 TO 49-YEAR-OLD FEMALES WITH AND WITHOUT DISABILITIES, IN ONTARIO, 2019/20



FINDINGS

- Pregnancy rates in females with developmental disabilities (28.8 pregnancies per 1,000 females) and multiple disabilities (29.5 per 1,000) were lower than that in females without a disability (49.4 per 1,000).
- Overall, 13.7% of pregnancies, or one in every eight pregnancies, were to females with a disability.

DISCUSSION

PREVALENCE OF DISABILITY AMONG REPRODUCTIVE-AGED FEMALES

Based on our data, 16.3% of reproductive-aged females in Ontario have a disability-related diagnosis. This estimate is similar to the Canadian Survey on Disability finding that 18% of 25 to 44-year-olds and 16% of 15 to 24-year-olds have a disability.[9] However, it is important to note that we were only able to measure diagnosed physical, sensory and developmental disabilities, whereas the Canadian Survey on Disability asks individuals to self-report their disability status.

PRECONCEPTION HEALTH

Most females in Ontario with and without disabilities experience adequate preconception health. However, there are important disparities experienced by females with disabilities, including higher rates of chronic physical and mental health conditions, use of medications that increase the risk of birth defects if taken in pregnancy, and experiences of interpersonal violence, as well as indicators of poverty in those with developmental and multiple disabilities specifically. Our findings are consistent with survey studies in the US.[11-13]

These preconception health disparities may be explained by broader social and structural factors such as experiences of ableism and discrimination that produce barriers to education and employment, and higher rates of unstable housing and food insecurity for people with disabilities.[18-20] They may also be explained by a lack of focus on preconception health, or reproductive health more broadly, in the medical care of disabled people.

PREGNANCY RATES

Pregnancy rates in Ontario are lower in females with disabilities compared to those without disabilities overall. However, one in eight pregnancies are to females with disabilities. These data extend what we know about pregnancy rates in people with disabilities from studies in the US.[14-17] Our findings suggest a larger proportion of pregnancies are to people with disabilities than was previously thought.[17]

Several factors might contribute to lower pregnancy rates in people with disabilities. Social factors could play a role, with many disabled people facing experiences of ableism and discrimination which could affect childbearing decision-making and opportunities.[21] Medical factors may include lower fertility associated with some conditions,[22] and complex decisions about pregnancy some people with disabilities experience, including how pregnancy might impact disability-related symptoms or progression and availability of medications that are safe in pregnancy.[23]

IMPLICATIONS FOR POLICY AND PRACTICE

Develop service-provider education on disability and preconception health

Evidence that one in eight pregnancies in Ontario are to people with a disability and that people with disabilities experience important preconception health disparities shows the need for service-provider education and training to understand and prioritize the preconception health needs of people with disabilities.[24] However, our qualitative interviews suggested preconception health, and reproductive health more broadly, tend to be neglected in the health care of people with disabilities. For example, an obstetrician-gynecologist explained that many health care providers tend to focus on disability needs only and assume their disabled patients are not sexually active:

> ***"Sometimes people forget that women with disabilities also have a sexual identity, right? And they just make an assumption that they're not sexually active when that's not true at all… And I think sometimes, people are so focused on this aspect of things [disability] that they forget all the other parts of being a human and [reproductive health] is one of them."***

DISCUSSION

IMPLICATIONS FOR POLICY AND PRACTICE

These assumptions, and lack of awareness among health care providers, were also seen in the experiences of Alyssa, who has cerebral palsy and wanted to discuss with her doctor a reproductive health concern she thought might impact her fertility. In response, her doctor encouraged her to take birth control:

"We found out I had polycystic ovarian syndrome [PCOS], so it was tricky because for a while my doctor was really resistant to do anything about that. I feel like he didn't really want to help me get pregnant; he kept putting me off for months. I kept coming back with more information of what I think is wrong. But he just goes 'Oh no, it's probably fine'. So it took about a year and then he sent me to a specialist who right away recognized I had PCOS and gave me some medication and it worked right away. But it was a little bit of a hassle… When I told my doctor I'd love a family, he just goes 'Oh, if you want a regular cycle, just go on birth control and don't worry about having a family,' which was frustrating."

Create preconception health resources for people with disabilities

Our findings also show a need for preconception health resources tailored to the needs of people with disabilities. Preconception health resources have been developed for people with chronic health conditions like diabetes and HIV,[7,8] but similar resources do not exist for people with disabilities.[25] Our interviews with people with disabilities suggest many desire and seek out preconception health information. Tanya, who has Marfan syndrome, commented, *"I went to see all my doctors before we decided to get pregnant and we made sure that, you know, it was safe for me, it was safe for the baby, and all of them gave us the green light so we felt comfortable."*

Preconception health care gives people with disabilities and their health care providers an opportunity to engage in health promotion and chronic condition management, make decisions about medication use in pregnancy, and, if relevant, discuss how pregnancy might impact disability-related symptoms and progression. Jennifer, who has rheumatoid arthritis, spoke about how physical health-related needs concerning medications and the impact of pregnancy on her disability were particularly important conversations for her to have prior to pregnancy:

"Yeah, certainly with the rheumatologist who was going over drugs and stuff, [disability-related symptoms were] a real concern… So I had a conversation with my rheumatologist and the fertility specialist referred us to the high-risk clinic even before we got pregnant… And I had done some research myself and I had some discussions with people I know who have rheumatoid arthritis who had pregnancies, and some people reported that their rheumatoid arthritis went into remission, but the rheumatologist said to me that a third go into remission, a third stay the same, and a third get worse."

Provide holistic preconception health care to people with disabilities

Beyond physical health-related needs, preconception health resources for people with disabilities should be holistic, addressing social determinants of health such as poverty and other structural barriers to health care. Preconception health resources should also take a trauma-informed approach, recognizing that people with disabilities experience higher rates of interpersonal violence than those without disabilities and are more likely to have a mental health condition.

A social worker described the need for this holistic approach:

"I think it's largely systemic, right? The number one label attached to our families and moms is 'disability,' right? And that part of their identity is really what the focus is on… And then there's a lack of kind of acknowledging or addressing the other identities, and pieces of them, that often have more of an impact on their day-to-day lives… They already have so many other things that they can't really hide: their skin colour, their socioeconomic status. Many of the women have really extensive trauma backgrounds… with intimate partner violence, sexual violence. Just, there's just so much they are up against…"

DISCUSSION

DATA NEEDS

Although our data provide an overview of the preconception health and pregnancy rates of females with disabilities in Ontario, there are several limitations that reflect ongoing data needs:

- We were unable to measure other equity indicators, such as race/ethnicity and gender identity, that might have been useful for identifying population subgroups with greater preconception health disparities.
- For social determinants of health, we only had indicators of income, marginalization and residential instability at the neighbourhood level. Given other research showing barriers to education and employment, housing instability and food insecurity experienced by disabled people,[18-20] our data likely underestimate the social disparities experienced by people with disabilities in Ontario.
- We were unable to measure other indicators relevant to preconception health, such as smoking, alcohol use, nutrition, physical activity and obesity. Survey data suggest people with disabilities experience health disparities in these areas that could also be addressed in preconception health promotion efforts.[10-13]
- For pregnancy rates, we were not able to identify miscarriages that occurred at home. This means that our overall pregnancy rates may have been underestimated.

FUTURE RESEARCH

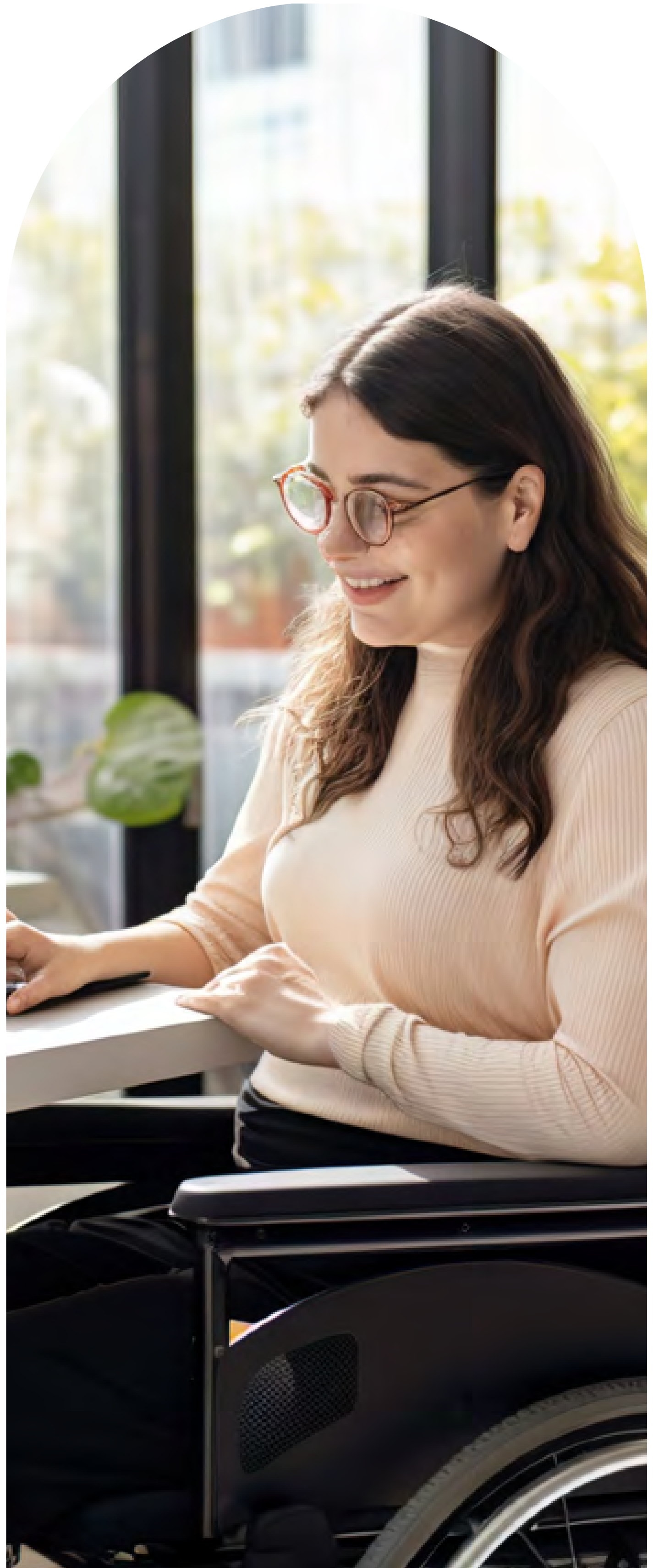
There are several areas where more research could help to inform policy and clinical practice related to preconception health care for people with disabilities. Informed by the perspectives and priorities of people with disabilities, these could include:

- Studies on preconception health disparities in people with disabilities facing other forms of oppression, for example, Black and Indigenous people with disabilities, or sexual and gender minority people with disabilities;
- Studies on the specific medications used by people with disabilities in the preconception period (e.g., pain and psychotropic medications) to inform medication counseling as a part of preconception health programs;
- Studies examining the preferred format and content of preconception health programs and services for people with disabilities; and
- Studies examining the effectiveness of such preconception health programs and services in reducing preconception health disparities between people with and without disabilities.

The results from this additional research could be used to create a more robust system of supports for all reproductive-aged people with disabilities and those planning a pregnancy.

Conclusion

This chapter shows females with disabilities represent at least 16.3% of all reproductive-aged females in Ontario. They experience disparities in the social determinants of health, physical health, mental health, medication use and interpersonal violence that may be preventable through better preconception care. Pregnancy rates are lower in people with disabilities compared to those without disabilities, but one in eight pregnancies are to people with disabilities. These data show a need for preconception health resources tailored to the needs of disabled people.



Related publications

- Brown HK, Chen S, Guttmann A, Havercamp SM, Parish S, Ray JG, et al. Rates of recognized pregnancy in women with disabilities in Ontario, Canada. *Am J Obstet Gynecol* 2020; 222(2):189–92.
- Tarasoff L, Lunsky Y, Chen S, Guttmann A, Havercamp S, Parish S, et al. Preconception health characteristics of women with disabilities in Ontario: a population-based, cross-sectional study. *J Womens Health* 2020; 29(12):1564–75.
- Tint A, Brown HK, Chen S, Lai M-C, Tarasoff LA, Vigod SN, et al. Health characteristics of reproductive-aged autistic women in Ontario: a population-based, cross-sectional study. *Autism* 2021; 25(4):1114–24.

RETURN TO PREVIOUS PAGE

References

1. World Health Organization. *Meeting to develop a global consensus on preconception care to reduce maternal and childhood mortality and morbidity.* Geneva: World Health Organization; 2012.
2. Atrash HK, Johnson K, Adams MM, Cordero JF, Howse J. Preconception care for improving perinatal outcomes: the time to act. *Matern Child Health J* 2006; 10:S3–11.
3. Grosse SD, Sotnikov SV, Leatherman S, Curtis M. The business case for preconception care: methods and issues. *Matern Child Health J* 2006; 10:S93–9.
4. Allen VM, Armson BA, Wilson RD, Johnson JA, Blight C, Gagnon A, et al. Teratogenicity associated with pre-existing and gestational diabetes. *J Obstet Gynaecol* Can 2007; 29:927–44.
5. Sedgh G, Singh S, Hussain R. Intended and unintended pregnancies worldwide in 2012 and recent trends. *Stud Fam Plann* 2014; 45:301–14.
6. Brown HK, Mueller M, Edwards S, Mill C, Enders J, Graves L, et al. Preconception health interventions delivered in public health and community settings: a systematic review. *Can J Public Health* 2017; 108(4):e388–97.
7. Nwolise CH, Carey N, Shawe J. Preconception care education for women with diabetes: a systematic review of conventional and digital health interventions. *J Med Internet Res* 2016; 18:e291.
8. Simone J, Hoyt MJ, Storm DS, Finocchario-Kessler S. Models of HIV preconception care and key elements influencing these services: findings from healthcare providers in seven US cities. *AIDS Patient Care STDS* 2018; 32(7):272–81.
9. Morris S, Fawcett G, Brisebois L, Hughes J. *A demographic, employment, and income profile of Canadians with disabilities aged 15 years and over, 2017.* Ottawa: Statistics Canada; 2018.
10. Centers for Disease Control and Prevention. Prevalence and most common causes of disability among adults – United States, 2005. *MMWR* 2009; 58(16):421–6.
11. Mitra M, Clements KM, Zhang J, Smith LD. Disparities in adverse preconception risk factors between women with and without disabilities. *Matern Child Health J* 2016; 20:507–15.
12. Kim M, Kim M, Kim H-J, Hong S, Fredriksen-Goldsen KI. Health disparities among childrearing women with disabilities. *Matern Child Health J* 2013; 17:1260–8.
13. Horner-Johnson W, Akovirshoev I, Amutah-Onukagha NN, Slaughter-Acey JC, Mitra M. Preconception health risks among US women: disparities at the intersection of disability and race or ethnicity. *Womens Health Issues* 2021; 31(1):65–74.
14. Iezzoni LI, Yu J, Wint AJ, Smeltzer SC, Ecker JL. Prevalence of current pregnancy among US women with and without chronic physical disabilities. *Med Care* 2013; 51:555–62.
15. Iezzoni LI, Yu J, Wint AJ, Smeltzer SC, Ecker JL. General health, health conditions, and current pregnancy among U.S. women with and without chronic physical disabilities. *Disabil Health J* 2014; 7:181–8.
16. Horner-Johnson W, Darney BG, Kulkarni-Rajasekhara S, Quigley B, Caughey AB. Pregnancy among US women: differences by presence, type, and complexity of disability. *Am J Obstet Gynecol* 2016; 214:529.e1–9.
17. Horner-Johnson W, Biel FM, Darney BG, Caughey AB. Time trends in births and cesarean deliveries among women with disabilities. *Disabil Health J* 2017; 10(3):376–81.
18. Garrels V, Høybråten Sigstad HM. Employment for persons with intellectual disability in the Nordic countries: a scoping review. *J Appl Res Intellect Disabil* 2021; 34(4):993–1007.
19. Roebuck M. Housing for people with intellectual disabilities: a scoping review. *J Dev Disabil* 2021; 26(2):1–25.
20. Brucker DL, Nord D. Food insecurity among young adults with intellectual and developmental disabilities in the United States: evidence from the National Health Interview Survey. *Am J Intellect Dev Disabil* 2016; 121(6):20–32.
21. Björnsdóttir K, Stefánsdóttir Á, Stefánsdóttir GV. People with intellectual disabilities negotiate autonomy, gender and sexuality. *Sex Disabil* 2017; 35(3):295–311.
22. Ha S, Martinez V. Associations between disability and infertility among US reproductive-aged women. *Int J Environ Res Public Health* 2021; 18(6):3202.
23. Meade T, Sharpe L, Hallab L, Aspanell D, Manolios N. Navigating motherhood choices in the context of rheumatoid arthritis: women's stories. *Musculoskeletal Care* 2012; 11(2):73–82.
24. Thierry JM. The importance of preconception care for women with disabilities. *Mat Child Health J* 2006; 10(S5):S175–6.
25. Horner-Johnson W, Moe E, Stoner RC, Klein KA, Edelman AB, Andresen EM, et al. Contraceptive knowledge and use among women with intellectual, physical, or sensory disabilities: a systematic review. *Disabil Health J* 2019;12(2):139–54.

JOHANNA lives in a large city with her husband and daughter. Johanna has muscular dystrophy, a physical disability that she describes as a "part of [her] identity as a person."

From what Johanna recalls, she and her husband have always wanted children. However, her doctors told her that there was a possibility that her muscular dystrophy could worsen as a result of hormonal changes if she got pregnant. So, when she became pregnant, Johanna had many questions for her health care providers. She initially encountered negative reactions from health care staff. For example, when making an appointment with a specialist, she said: *"I was talking to a nurse on the phone and she's like, 'Well, I don't understand. You want to have an abortion?' And I said, 'No. I want to talk to the doctor to see what my risks are.' And she's like—what did she say? It was so rude... She started counselling me on the phone, 'Well, do you feel ready to have a baby?' And I was like, 'I don't want to talk to you about this, I want to talk to my doctor about this.' It felt very patronizing."*

Johanna finally managed to find a pregnancy care clinic where she had a positive experience with a health care provider who had disability expertise. *"The appointment was lovely. The doctor was amazing and really helpful and supportive and said, 'Whatever you want to do, we'll be here for you. I'd love to take you on. We can support you, we have lots of clients like you. What we'll do is we'll get you to see a bunch of specialists to make sure your breathing's okay, but we'll do that here'. So, she made me feel very supported and I had this team that was going to be behind me."*

During the course of her pregnancy, Johanna saw several specialists,including a respirologist, a neurologist, an anaesthesiologist and an occupational therapist. A meeting was organized to discuss Johanna's birth plan with her entire health care team. Johanna said the meeting made her *"feel good because everybody was in the room and listening to me... I made them go through the birth plan multiple times like, 'How am I going to be transferred? Who's going to be doing it?'"* She said that having this plan in place made the process of labour and delivery go *"smoothly."*

When asked what advice she would give service-providers caring for pregnant people with disabilities, Johanna said: *"You need to ask new questions to capture the person's experiences. I think the biggest thing is that I appreciate when people listen to me and don't assume what they think, like if they think, 'I've worked with disabled people before, I know about this'."*

Based on an interview with a study participant. The name and details have been changed for privacy.

03

Pregnancy Outcomes

MAIN MESSAGES

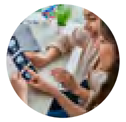
- **Adequate access to high-quality prenatal care reduces the risk of pregnancy complications.**
- **We describe outpatient prenatal care access, emergency department visits and hospital admissions, and physical health, mental health and experiences of interpersonal violence in pregnancy among females with and without disabilities in Ontario with a birth between 2010/11 and 2019/20.**
- **Most females in Ontario first received prenatal care in the first trimester and received the recommended number of visits, but those with developmental disabilities experienced disparities in these indicators.**
- **Females with disabilities were more likely than those without disabilities to have emergency department visits and hospital admissions in pregnancy.**
- **Females with disabilities were also more likely than those without disabilities to experience rare but serious physical health complications, as well as mental health conditions and interpersonal violence during pregnancy.**
- **Coordinated, multi-disciplinary prenatal care that is responsive to the needs of pregnant people with disabilities is required.**

Introduction

Adequate access to high-quality prenatal care reduces the risk of pregnancy complications such as stillbirth and preterm birth.[1] According to Society of Obstetricians and Gynaecologists of Canada guidelines, prenatal care should start in the first eight to 10 weeks of pregnancy, and there should be 11 to 14 prenatal care visits throughout pregnancy.[2] Late or infrequent prenatal care visits,[1] as well as emergency department visits and hospital admissions during pregnancy,[3] signal that more could be done to connect pregnant patients with high-quality outpatient care to prevent avoidable complications. Likewise, measures of physical health, mental health and other needs of pregnant people are critical for informing the content and structure of prenatal care. For example, elevated rates of serious physical health complications could reflect the need for more frequent and longer prenatal care visits to monitor patients' health more closely,[1] while mental illness or exposure to interpersonal violence in pregnancy may show a need for specialized resources, such as trauma-informed care.[4] Currently, guidelines for the optimal prenatal care of people with disabilities are limited.[5,6]

To inform the development of high-quality prenatal care for people with disabilities, the main questions this chapter will answer are:

- How does prenatal care access in females with disabilities compare to those without disabilities?
- Are females with disabilities more likely than those without disabilities to have emergency department visits and hospital admissions in pregnancy?
- Are females with disabilities more likely than those without disabilities to experience serious physical health complications, mental health conditions and interpersonal violence in pregnancy?



BACKGROUND

ACCESS TO OUTPATIENT PRENATAL CARE

There have been few quantitative studies examining prenatal care access in people with disabilities. One study using California health administrative data showed people with developmental disabilities and d/Deaf people were more likely than those without disabilities to experience late entry into prenatal care and that they, along with people with vision loss, received fewer than the recommended number of prenatal care visits.[7] On the other hand, people with physical disabilities had earlier access to prenatal care and received more than the recommended number of visits.[7] Similar findings have been reported in surveys in the UK.[8] However, surveys often exclude people who are the most under-served. Ontario population-based data allow us to understand prenatal care access in the entire population in the context of our universal health care system.

In this chapter, access to prenatal care is measured using two indicators available in health administrative data:[9] receipt of the first prenatal care visit in the first trimester and receipt of the recommended number of prenatal care visits.[2] We report the proportion of 15 to 49-year-old females with physical, sensory, developmental and multiple disabilities, and without disabilities, with a birth in Ontario between 2010/11 and 2019/20, who had each indicator. For more details on how prenatal care access was measured, refer to the Technical Appendix.

Prenatal care access
Prenatal care access is defined by the timing and number of outpatient prenatal care visits with an obstetrician or general practitioner/family physician for the purposes of health promotion and disease prevention in pregnancy, relative to Society of Obstetricians and Gynaecologists of Canada guidelines.[2]

EMERGENCY DEPARTMENT VISITS AND HOSPITAL ADMISSIONS IN PREGNANCY

Several quantitative studies have examined emergency department visits and hospital admissions in pregnancy in people with disabilities. For example, studies using linked survey and health administrative data in the US showed people with disabilities, and those with developmental disabilities in particular, were more likely than people without disabilities to have emergency department visits and hospital admissions in pregnancy.[10,11] A study using Medicaid data showed similar results.[12] Ontario data are needed to understand hospital care patterns in pregnant people with disabilities within a universal health care system.

In this chapter, we measure emergency department visits and hospital admissions in pregnancy. We report the proportions of 15 to 49-year-old females with physical, sensory, developmental and multiple disabilities, and without disabilities, with a birth in Ontario between 2010/11 and 2019/20, who had an emergency department visit or a hospital admission in pregnancy, overall and for obstetric, other medical and psychiatric reasons. For more details on how emergency department visits and hospital admissions were measured, refer to the Technical Appendix.

Emergency department visits and hospital admissions in pregnancy
Emergency department visits are unscheduled visits by patients who may need immediate care in facilities staffed by physicians around the clock, seven days per week.[13] Hospital admissions are planned and unplanned inpatient hospital stays. These are further defined according to the diagnosis used to describe the primary reason for the encounter, as being for obstetric, other medical or psychiatric reasons.

BACKGROUND

PHYSICAL HEALTH, MENTAL HEALTH, AND OTHER NEEDS IN PREGNANCY

There are a number of quantitative studies on the physical health of people with disabilities in pregnancy. These studies were summarized in a meta-analysis by our team, which showed people with disabilities have elevated risks of common pregnancy complications, such as gestational diabetes and gestational hypertension.[14] However, there is a lack of data on serious physical health complications (e.g., hemorrhage, sepsis),[14] which, though rare, are life-threatening.[1] There is also a lack of data on mental health[15] and interpersonal violence in pregnancy.[16,17] Data on these outcomes are needed to inform the content and structure of prenatal care for disabled people.

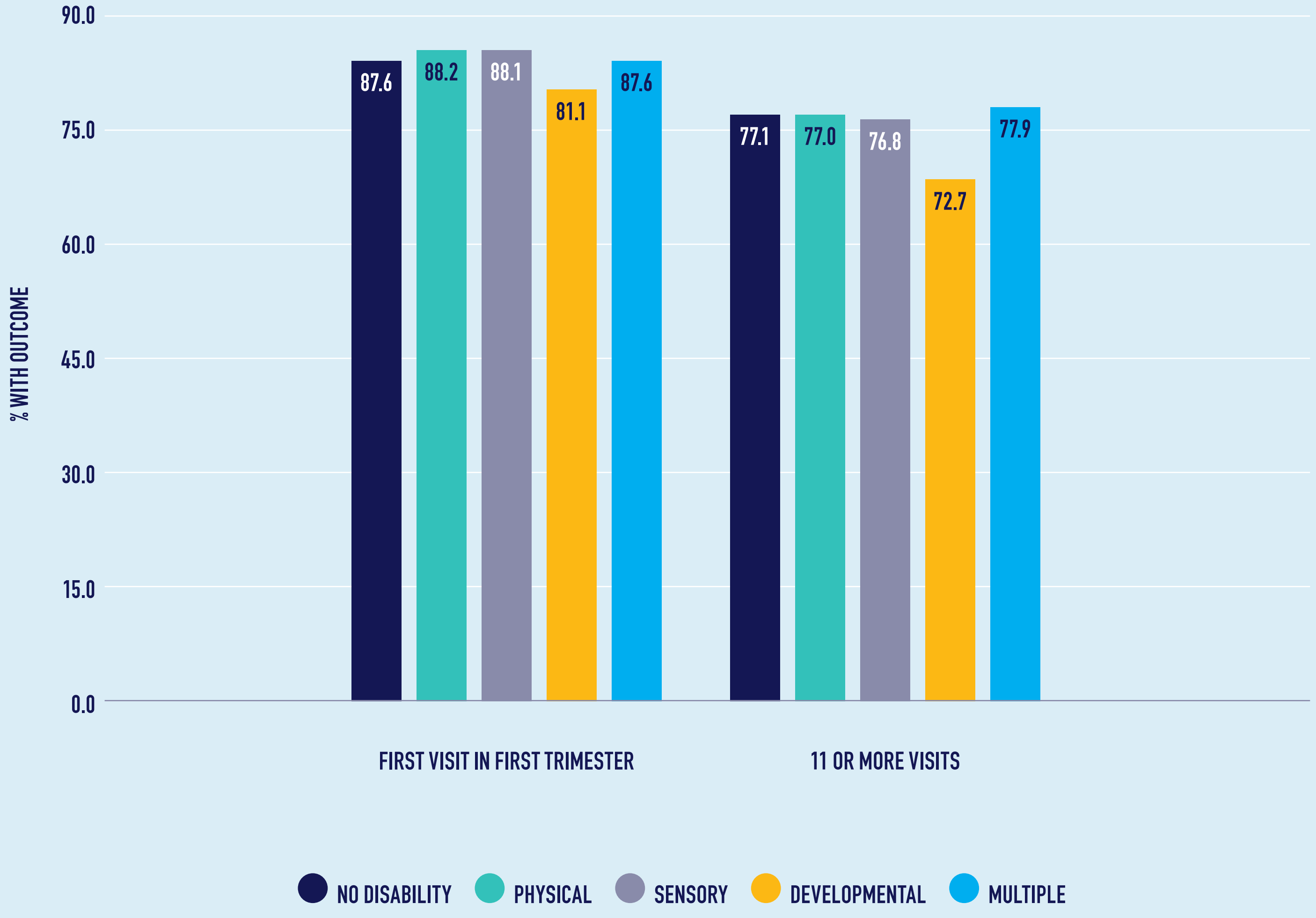
In this chapter, we measure indicators of physical health, mental health and interpersonal violence in pregnancy. First, we report the proportion of 15 to 49-year-old females with physical, sensory, developmental and multiple disabilities, and without disabilities, with a birth in Ontario between 2010/11 and 2019/20, who experienced a serious physical health complication in pregnancy.[18] Second, we report the proportion who had a health care encounter for a mood or anxiety, psychotic, substance use or other mental disorder, or self-harm. Third, we report the proportion who experienced an emergency department visit for interpersonal violence.[19] For more details on how these indicators were measured, refer to the Technical Appendix.

Physical health, mental health and interpersonal violence
Physical health is defined by the occurrence of serious physical health complications (e.g., hemorrhage, sepsis, intensive care unit admission or death) between conception and delivery.[18] Mental health is defined by physician visits, emergency department visits and hospital admissions for a mood or anxiety, psychotic, substance use or other mental disorder, and emergency department visits for self-harm between conception and delivery. Interpersonal violence is defined as an emergency department visit for assault or other maltreatment between conception and delivery.[19]

EXHIBITS AND FINDINGS

EXHIBIT 3.1

INDICATORS OF PRENATAL CARE ACCESS AMONG 15 TO 49-YEAR-OLD FEMALES WITH AND WITHOUT DISABILITIES, IN ONTARIO, 2010/11–2019/20



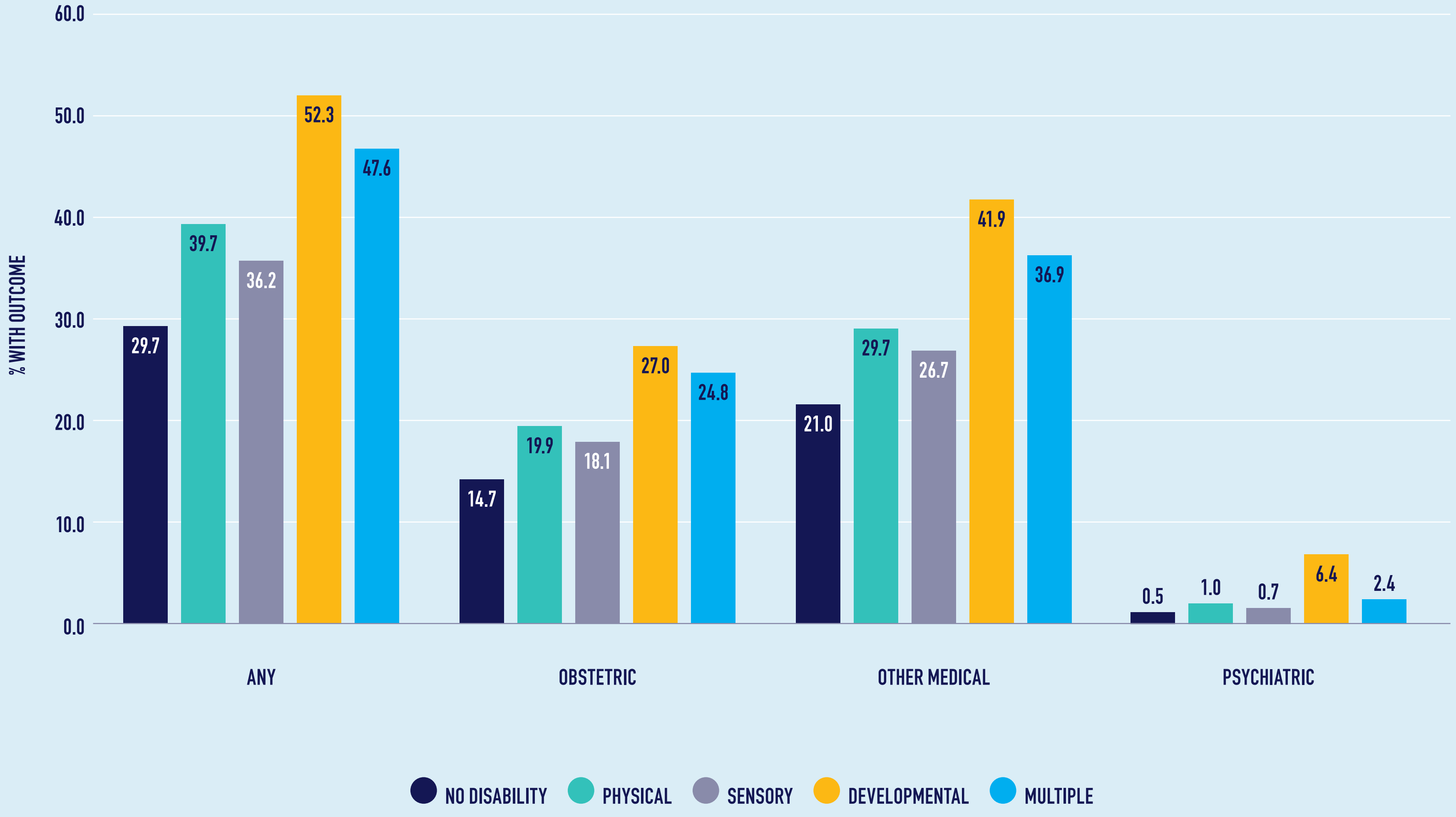
FINDINGS

- Most females in Ontario had adequate prenatal care access.
- Females with developmental disabilities (81.1%) were less likely than those without a disability (87.6%) to begin receiving prenatal care in the first trimester.
- Females with developmental disabilities (72.7%) were less likely than those without a disability (77.1%) to receive the recommended number of prenatal care visits.

EXHIBITS AND FINDINGS

EXHIBIT 3.2

PREVALENCE OF EMERGENCY DEPARTMENT VISITS IN PREGNANCY AMONG 15 TO 49-YEAR-OLD FEMALES WITH AND WITHOUT DISABILITIES, IN ONTARIO, 2010/11–2019/20



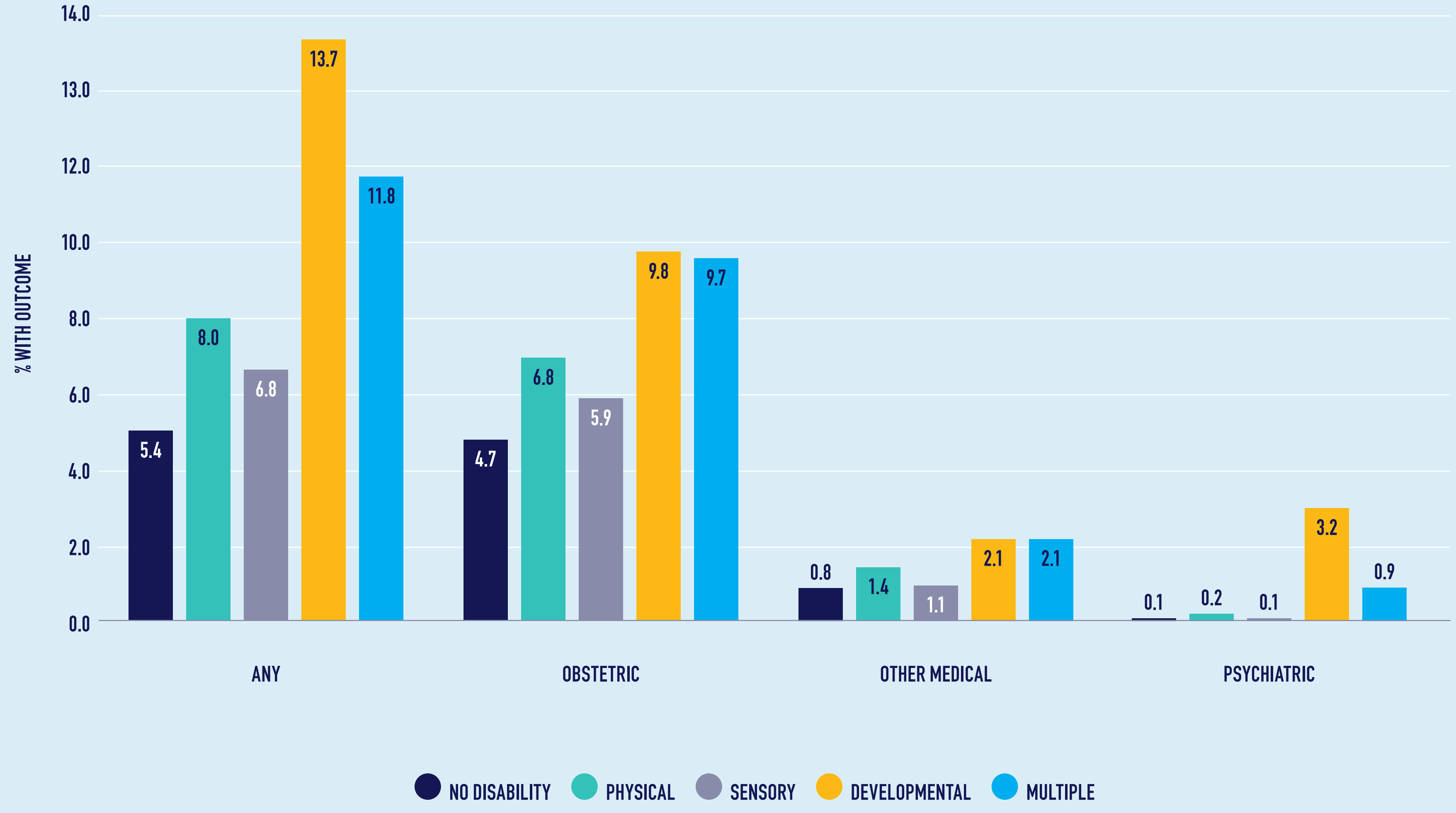
FINDINGS

- Many females in Ontario had an emergency department visit in pregnancy.
- Emergency department visits for obstetric reasons in pregnancy were more common in females with physical (19.9%), developmental (27.0%), and multiple disabilities (24.8%) than in those without a disability (14.7%).
- Emergency department visits for other medical reasons in pregnancy were more common in females with physical (29.7%), sensory (26.7%), developmental (41.9%), and multiple disabilities (36.9%) than in those without a disability (21.0%).
- Emergency department visits for psychiatric reasons in pregnancy were more common in females with developmental (6.4%) and multiple disabilities (2.4%) than in those without a disability (0.5%).

EXHIBITS AND FINDINGS

EXHIBIT 3.3

PREVALENCE OF HOSPITAL ADMISSIONS IN PREGNANCY AMONG 15 TO 49-YEAR-OLD FEMALES WITH AND WITHOUT DISABILITIES, IN ONTARIO, 2010/11–2019/20



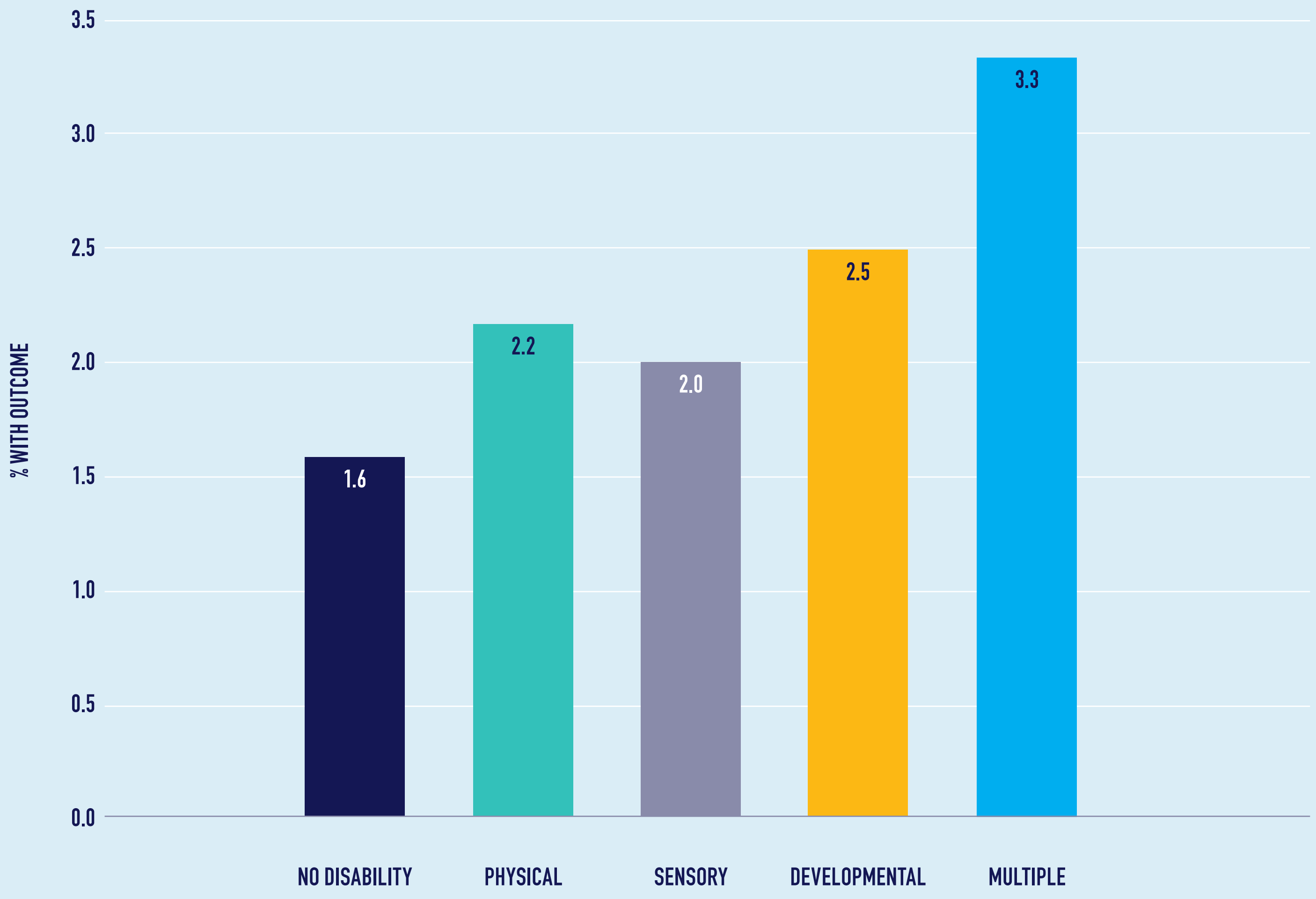
FINDINGS

- Hospital admissions for obstetric reasons in pregnancy were more common in females with developmental (9.8%) and multiple disabilities (9.7%) than in those without a disability (4.7%).
- Hospital admissions for other medical reasons in pregnancy were more common in females with developmental (2.1%) and multiple disabilities (2.1%) than in those without a disability (0.8%).
- Hospital admissions for psychiatric reasons in pregnancy were more common in females with developmental (3.2%) and multiple disabilities (0.9%) than in those without a disability (0.1%).

EXHIBITS AND FINDINGS

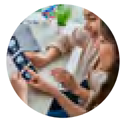
EXHIBIT 3.4

PREVALENCE OF SERIOUS PHYSICAL HEALTH COMPLICATIONS IN PREGNANCY AMONG 15 TO 49-YEAR-OLD FEMALES WITH AND WITHOUT DISABILITIES, IN ONTARIO, 2010/11–2019/20



FINDINGS

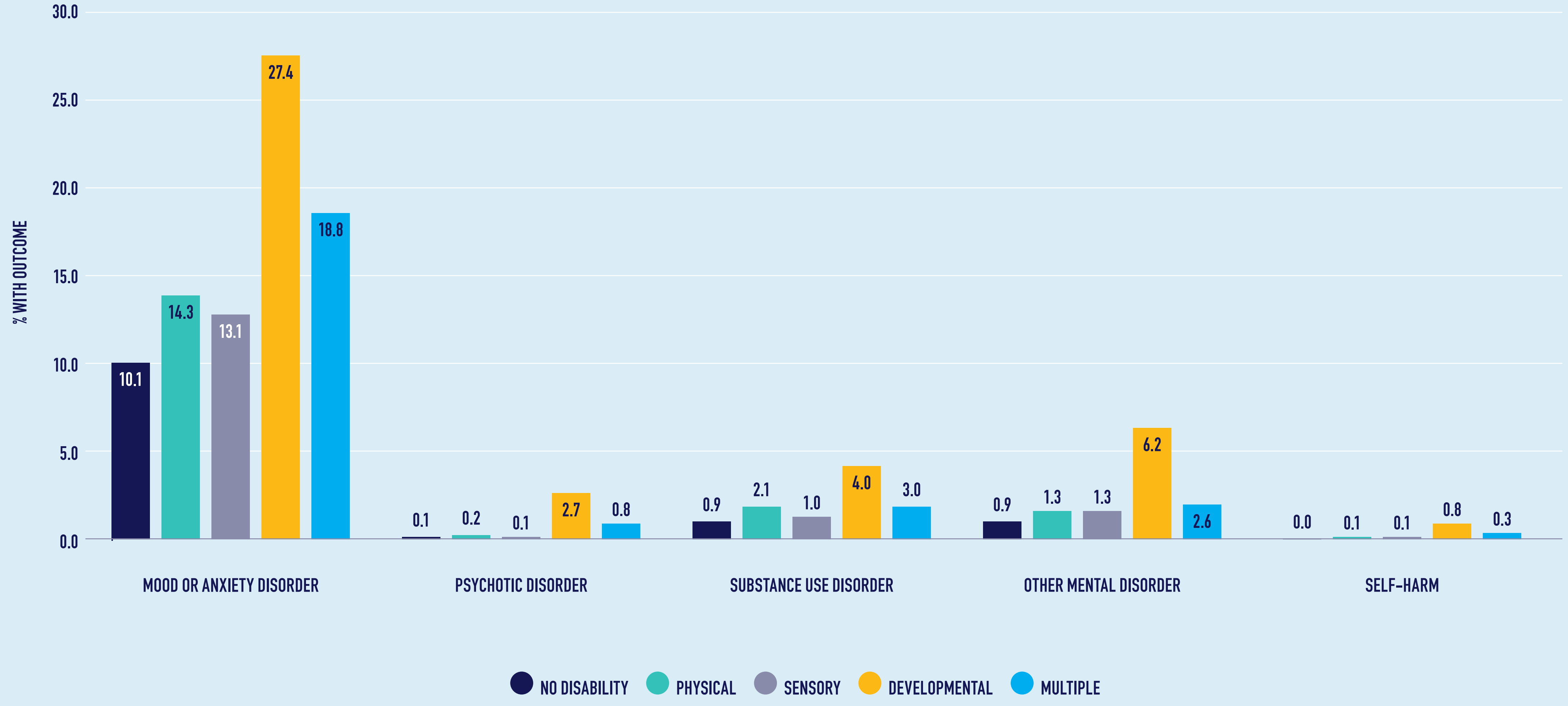
- Serious physical health complications were rare for females in Ontario overall.
- Females with multiple disabilities (3.3%) were more likely than those without a disability (1.6%) to experience serious physical health complications in pregnancy.



EXHIBITS AND FINDINGS

EXHIBIT 3.5

PREVALENCE OF MENTAL HEALTH CONDITIONS IN PREGNANCY AMONG 15 TO 49-YEAR-OLD FEMALES WITH AND WITHOUT DISABILITIES, IN ONTARIO, 2010/11–2019/20



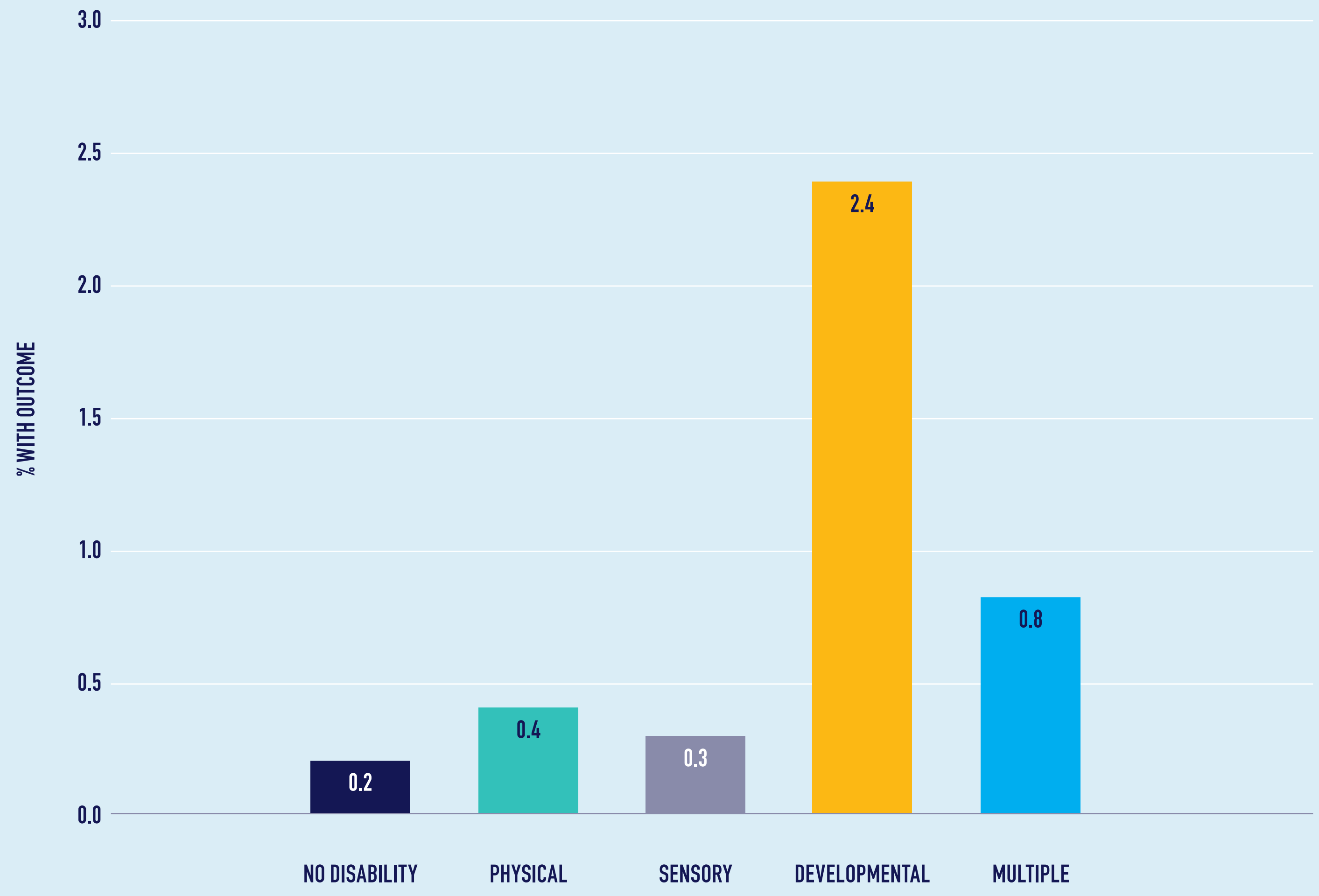
FINDINGS

- Mood and anxiety disorders in pregnancy were more common in females with physical (14.3%), developmental (27.4%), and multiple disabilities (18.8%) than in those without a disability (10.1%).
- Psychotic disorders in pregnancy were more common in females with developmental (2.7%) and multiple disabilities (0.8%) than in those without a disability (0.1%).
- Substance use disorders in pregnancy were more common in females with physical (2.1%), developmental (4.0%), and multiple disabilities (3.0%) than in those without a disability (0.9%).
- Other mental disorders in pregnancy were more common in females with developmental (6.2%) and multiple disabilities (2.6%) than in those without a disability (0.9%).
- Self-harm in pregnancy was more common in females with developmental disabilities (0.8%) than in those without a disability (0.0%).

EXHIBITS AND FINDINGS

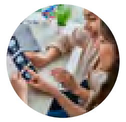
EXHIBIT 3.6

PREVALENCE OF INTERPERSONAL VIOLENCE IN PREGNANCY AMONG 15 TO 49-YEAR-OLD FEMALES WITH AND WITHOUT DISABILITIES, IN ONTARIO, 2010/11–2019/20



FINDINGS

- Emergency department visits for interpersonal violence in pregnancy were rare for females in Ontario overall.
- Females with developmental disabilities (2.4%) were more likely than those without a disability (0.2%) to have an emergency department visit for interpersonal violence in pregnancy.



DISCUSSION

ACCESS TO OUTPATIENT PRENATAL CARE

Based on our data, most females in Ontario receive prenatal care in the first trimester and receive the recommended number of visits. However, there were some disparities, particularly for those with developmental disabilities. These findings are similar to studies in the US[7] and UK.[8] Disparities in these indicators were also seen for people with sensory disabilities in prior research in the US,[6] but not in our study. This discrepancy may be due to differences between Canadian and American health care systems.

Disparities in prenatal care access for people with developmental disabilities may be explained by structural factors such as systemic barriers to sexual health education that might result in delays in recognizing the signs of pregnancy,[20] or practical issues such as a lack of transportation. People with developmental disabilities may also feel reluctant to seek prenatal care due to ableist health care provider attitudes about their parenting abilities and fears of child welfare involvement.[21] On the other hand, people with physical disabilities, who did not have disparities in the timing and number of prenatal care visits, may already be connected to health care prior to pregnancy due to elevated medical needs and may thus have a smoother transition into prenatal care.

EMERGENCY DEPARTMENT VISITS AND HOSPITAL ADMISSIONS IN PREGNANCY

Emergency department visits are common in pregnancy in females in Ontario, but females with disabilities have higher rates of emergency department visits compared to those without disabilities. Hospital admissions also occur more frequently in females with versus without disabilities. These findings are consistent with studies in the US showing elevated rates of hospital care in pregnant people with disabilities.[10-12]

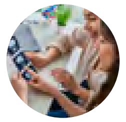
High rates of hospital care in pregnant people with disabilities may reflect a lack of access to high-quality outpatient care, which may result in preventable complications or seeking emergency care for non-urgent needs.[3] Other contributors might include exacerbations of underlying physical or mental health conditions in pregnancy.[3]

PHYSICAL HEALTH, MENTAL HEALTH AND OTHER NEEDS IN PREGNANCY

Serious physical health complications are rare in females in Ontario. However, females with multiple disabilities have higher rates of these complications than those without disabilities. Most prior studies have only been able to examine common, but less serious, pregnancy complications such as gestational diabetes and gestational hypertension.[14] Our data therefore address an important gap in the literature. Observed disparities in rare, but serious, physical health complications may be explained by broader social determinants of health such as poverty,[22] as well as elevated rates of chronic conditions in people with disabilities, such as diabetes mellitus and chronic hypertension, that are known risk factors for serious complications in pregnancy.[17]

Mental health conditions in pregnancy are also more common in females with disabilities compared to those without disabilities. This finding is consistent with a survey from the US that showed elevated rates of prenatal mental illness in people with disabilities,[15] and with research outside of pregnancy suggesting people with disabilities have elevated rates of mental illness.[23] These elevated rates of mental illness have multiple contributors, including poverty, low social support and challenges accessing timely mental health care.[24]

Experiences of interpersonal violence in pregnancy resulting in an emergency department visit are rare in Ontario; however, females with developmental disabilities are more likely to experience this outcome than those without disabilities. This finding is consistent with a handful of studies examining exposure to intimate partner violence in pregnant people with disabilities in the US.[16,17] These disparities may be explained by a lack of accessible violence-related resources and services; stigma and stereotypes that reduce personal agency; and economic and disability-related needs that increase reliance of pregnant people with disabilities on others.[25]



DISCUSSION

IMPLICATIONS FOR POLICY AND PRACTICE

Address practical barriers to prenatal care

Elevated rates of hospital care and pregnancy complications in people with disabilities, and particularly those with developmental and multiple disabilities, show the need to address barriers to outpatient prenatal care. This includes addressing practical barriers to care, such as availability of accessible and affordable transportation. In our qualitative interviews, for example, a family physician who provides low-risk obstetrical care, explained, *"[People with disabilities] often present [to prenatal care] later on in pregnancy in my experience… It's sometimes just the logistics of getting to an ultrasound or getting to places is just hard, so they miss appointments."*

Develop accessible prenatal care services and technologies

Elevated rates of pregnancy complications in people with disabilities also show the need to ensure that prenatal care services and medical technologies to manage pregnancy complications address accessibility needs. Our interviews showed considerable inaccessibility in prenatal care. For example, Siobhan, who is blind and had gestational diabetes, described how difficult it was for her to monitor her blood glucose:

> ***"It was very hard to have a little strip and you have to hold the tiny end of the strip to this droplet of blood on your finger and you can't touch the droplet of blood with the strip. So, I found it really challenging to try and get it to read properly. And I needed to take that four times a day, so that meant I actually always needed to find a sighted person to help me do that."***

Provide patient-centred, multidisciplinary prenatal care

Given the complexity of the physical and mental health needs observed in people with disabilities, our findings suggest the value of multidisciplinary prenatal care, which includes access to not only obstetrical care providers, but also other medical specialists and allied health professionals to support physical and mental health concerns. Johanna, who has muscular dystrophy and osteoporosis, described the health care providers involved in her care:

> ***"I had a respirologist and anesthesiologist, neurologist… I went back to see my occupational therapist that I already had there to do some pregnancy stuff. I saw a physiatrist there who I consulted with… My doctor I think just used her magic so I would get in. Every time, they would just fit me in."***

While multidisciplinary medical care may be helpful for many patients with disabilities, others may benefit from coordination of obstetrical care and social or disability-related supports in the community to promote their overall health and wellbeing. For example, when asked what services would be most helpful for pregnant people with developmental disabilities, a family physician said:

> ***"I think having some sort of social support is useful. Some family health teams in Ontario have these community services workers, through the Health Links program, which is ending, sadly. But basically, I think of the position as sort of a resource navigator. So, I have somebody who's pregnant with a developmental disability, I could say, 'Hey, do you know of any resources that could help this person?' And she's been fantastic because she sort of helps to link to the various resources that are out there."***

Such multidisciplinary care in pregnancy requires coordination to avoid placing a burden on the patient. Care coordination might be accomplished through a social worker or "patient navigator" who could bring together the different service-providers involved in prenatal care. Luciana, who has fibromyalgia, rheumatoid arthritis, and Sjögren's Syndrome, noted how useful such coordination would have been for her pregnancy care: *"… And I wish there was a social worker or something… I didn't feel my providers were communicating that well."*

DISCUSSION

Train service-providers on the delivery of disability-affirming prenatal care

Disparities in prenatal care access, and elevated rates of emergency department visits and hospital admissions, in pregnant people with disabilities signal unmet care needs and show the importance of training service-providers in the delivery of disability-affirming prenatal care, where patients feel safe accessing services. The importance of this training is illustrated in our interviews with people with disabilities; Maria, who has a developmental disability, explained her fears about seeking prenatal care:

> *"I started late because I was nervous at first, so I went to see my obstetrician when I was about four months pregnant… So, I was kind of scared to because I didn't know what to do… I was scared because I wasn't sure what to do with my third child because, you know, it was hard for me…"*

Develop patient resources on disability and pregnancy

There is also a need to develop patient resources, with information on what to expect during pregnancy and when to seek different types of care. Many people with disabilities we interviewed noted having questions about pregnancy complications and what to do to avoid them, and struggled to find this information. For example, Alyssa, who has cerebral palsy and sometimes experiences falls, described not knowing when to call her doctor:

> *"With cerebral palsy, I'm more likely to have a fall. In the early stage of pregnancy, I slipped, I had a fall, and I was really afraid that that wasn't good… I was calling my doctor trying to get through, and it was difficult to… I guess maybe I should have had clarification beforehand about when I should be concerned and what I should try to avoid. But yeah, it was difficult, I guess sometimes, to really feel heard."*

DISCUSSION

DATA NEEDS

Our findings should be interpreted in the context of several limitations:

- While we were able to measure the quantity of outpatient prenatal care received, we were unable to measure the quality of care. The quality of pregnancy care for people with disabilities is explored in detail in Chapter 6.
- Our measure of mental health conditions only captures conditions that result in a health care encounter with a physician. If disabled people are less likely to seek care for their symptoms, or are more likely to receive care with a non-physician (e.g., social worker), their rates of mental illness may have been underestimated.
- We were unable to measure experiences of interpersonal violence that did not result in an emergency department visit. Given the barriers people with disabilities experience accessing violence-related services,[25] rates of interpersonal violence are likely underestimated. We also had no perpetrator data, but other research has shown that most violence experienced around the time of pregnancy is by an intimate partner.[26]

FUTURE RESEARCH

There are several areas where more research could help to inform policy and clinical practice related to prenatal care for people with disabilities, including:

- Studies on prenatal care access and prenatal health disparities in people with disabilities facing other forms of oppression, for example, Black and Indigenous people with disabilities, as well as sexual and gender minority people with disabilities;
- Studies on social and structural factors that contribute to higher rates of hospital care, serious physical health complications, and mental health conditions in pregnant people with disabilities; and
- Studies on the effectiveness of services and supports that improve the multidisciplinarity and coordination of prenatal care for people with disabilities.

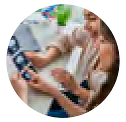
The results of such studies could be used to help inform new areas of improvement in the prenatal care of people with disabilities to better meet their needs.

Conclusion

This chapter shows that most females in Ontario receive prenatal care in the first trimester and receive the recommended number of visits, but those with developmental disabilities experience important disparities in these indicators. Females with disabilities are more likely than those without disabilities to require hospital care in pregnancy. Females with disabilities, and especially developmental and multiple disabilities, are also more likely to experience serious physical health complications, mental health conditions and interpersonal violence. Coordinated, multidisciplinary prenatal care that is responsive to the needs of people with disabilities is required.

Related publications

- Brown HK, Ray JG, Chen S, Guttmann A, Havercamp S, Parish S, et al. Association of pre-existing disability and severe maternal morbidity or mortality in Ontario, Canada. *JAMA Netw Open* 2021; 4(1):e2034993.
- Brown HK, Saunders N, Chen S, Leslie K, Vigod SN, Fung K, et al. Disability and interpersonal violence in the perinatal period. *Obstet Gynecol* 2022; 140(5):797–805.
- Brown HK, Varner C, Ray JG, Scime N, Fung K, Guttmann S, et al. Comparison of emergency department use between pregnant people with and without disabilities in Ontario, Canada. *JAMA Netw Open* 2023; 6(8):e2327185.
- Brown HK, Vigod SN, Chen S, Guttmann A, Havercamp S, Parish S, et al. Perinatal mental illness among women with disabilities: a population-based cohort study. *Soc Psych Psychiatr Epidemiol* 2022; 57(11):2217–28.
- Kassee C, Lunsky Y, Patrikar A, Brown HK. Impact of social-, health-, and disability-related factors on pregnancy outcomes in women with intellectual and developmental disabilities: a population-based latent class analysis. *Disabil Health J* 2023; 6(2):101426.
- Nishat F, Lunsky Y, Tarasoff LA, Brown HK. Prenatal care adequacy among women with disabilities: a population-based study. *Am J Prev Med* 2022; 62(1):39–49.
- Nishat F, Lunsky Y, Tarasoff LA, Brown HK. Continuity of primary care and prenatal care adequacy among women with disabilities in Ontario: a population-based cohort study. *Disabil Health J* 2022; 15(3):101322.



RETURN TO PREVIOUS PAGE

References

1. Heaman MI, Martens PJ, Brownell MD, Chartier MJ, Derksen SA, Helewa ME. The association of inadequate and intensive prenatal care with maternal, fetal, and infant outcomes: a population-based study in Manitoba, Canada. *J Obstet Gynaecol Can* 2019; 41(7):947–59.
2. Society of Obstetricians and Gynaecologists of Canada. *Healthy beginnings: Guidelines for care during pregnancy and childbirth.* Ottawa: SOGC; 1998.
3. Malik S, Kothari C, MacCallum C, Liepman M, Tareen S, Rhodes KV. Emergency department use in the perinatal period: an opportunity for early intervention. *Ann Emerg Med* 2017; 70(6):835–9.
4. Sperlich M, Seng JS, Li Y, Taylor J, Bradbury-Jones C. Integrating trauma-informed care into maternity care practice: conceptual and practical issues. *J Midwifery Womens Health* 2017; 62(6):661–72.
5. Berndl A, Ladhani N, Wilson RD, Basso M, Jung E, Tarasoff LA, et al. Guideline No. 416: labour, delivery, and postpartum care for people with physical disabilities. *J Obstet Gynaecol Can* 2021; 43(6):769–80.
6. Sullivan WF, Diepstra H, Heng J, Ally S, Bradley E, Casson I, et al. Primary care of adults with intellectual and developmental disabilities: 2018 Canadian consensus guidelines. *Can Fam Physician* 2018; 64(4):254–79.
7. Homer-Johnson W, Biel FM, Caughey AB, Damey BG. Differences in prenatal care by presence and type of maternal disability. *Am J Prev* Med 2019; 56(3):376–82.
8. Redshaw M, Malouf R, Gao H, Gray R. Women with disability: the experience of maternity care during pregnancy, labour and birth and the postnatal period. *BMC Pregnancy Childbirth* 2013; 13:174.
9. Alexander GR, Kotelchuck M. Quantifying the adequacy of prenatal care: a comparison of indices. *Public Health Rep* 1996; 111(5):408–18.
10. Clements KM, Mitra M, Zhang J. Antenatal hospital utilization among women at risk for disability. *J Womens Health* 2018; 27(8):1026-1034.
11. Mitra M, Parish SL, Clements KM, Zhang J, Moore Simas TA. Antenatal hospitalization among US women with intellectual and developmental disabilities: a retrospective cohort study. *Am J Intellect Dev Disabil* 2018; 123(5):399–411.
12. Gavin NI, Benedict MB, Adams EK. Health service use and outcomes among disabled Medicaid pregnant women. *Womens Health Issues* 2006; 16(6):313–22.
13. Varner CE, Park AL, Little D, Ray JG. Emergency department use by pregnant women in Ontario: a retrospective population-based cohort study. *CMAJ Open* 2020; 8(2):E304–12.
14. Tarasoff LA, Ravindran S, Malik H, Salaeva D, Brown HK. Maternal disability and risk for pregnancy, delivery, and postpartum complications: a systematic review and meta-analysis. A*m J Obstet Gynecol* 2020; 222(1):27.e1–27.e32.
15. Alhusen JL, Hughes RB, Lyons G, Laughon K. Depressive symptoms during the perinatal period by disability status: findings from the United States Pregnancy Risk Assessment Monitoring System. *J Adv Nurs* 2022; 79(1):223–33.
16. Mitra M, Manning SE, Lu E. Physical abuse around the time of pregnancy among women with disabilities. *Maternal Child Health J* 2012; 16:802–6.
17. Mwachofi AK. Violence against pregnant women with disabilities. *J Health Disparities Res Pract* 2016; 9(2):28–45.
18. Ray JG, Park AL, Dzakpasu S, Dayan N, Deb-Rinker P, Luo W, et al. Prevalence of severe maternal morbidity and factors associated with maternal mortality in Ontario, Canada. *JAMA Netw Open* 2018; 1(7):e184571.
19. Saunders N, Plumptre L, Diong C, Gandhi S, Schull M, Guttmann A, et al. Acute care visits for assault and maltreatment before vs during the COVID-19 pandemic in Ontario, Canada. *JAMA Health Forum* 2021; 2:e211983.
20. Grove L, Morrison-Beedy D, Kirby R, Hess J. The birds, bees, and special needs: making evidence-based sex education accessible for adolescents with intellectual disabilities. *Sex Disabil* 2018; 36:313–29.
21. Tøssebro J, Midio T, Paulsen V, Berg B. Prevalence, trends and custody among children of parents with intellectual disabilities in Norway. *J Appl Res Intellect Disabil* 2017; 30(3): 533–42.
22. Thomson K, Moffat M, Arisa O, Jesurasa A, Richmond C, Odeniyi A, et al. Socioeconomic inequalities and adverse pregnancy outcomes in the UK and Republic of Ireland: a systematic review and meta-analysis. *BMJ Open* 2021; 11(3):e042753.
23. Havercamp SM, Scott HM. National health surveillance of adults with disabilities, adults with intellectual and developmental disabilities, and adults with no disabilities. *Disabil Health J* 2015; 8(2):165–72.
24. Robertson E, Grace S, Wallington T, Stewart DE. Antenatal risk factors for postpartum depression: a synthesis of recent literature. *Gen Hosp Psych* 2004; 26(4):289–95.
25. Hughes K, Bellis MA, Jones L, Wood S, Bates G, Eckley L, et al. Prevalence and risk of violence against adults with disabilities: a systematic review and meta-analysis of observational studies. *Lancet* 2012; 379:1621–9.
26. National Center for Injury Prevention and Control. *National Intimate Partner and Sexual Violence Survey: 2015 data brief – updated release.* Atlanta: Centers for Disease Control and Prevention; 2018.

GARIMA is a single mother from the suburb of a large city, who describes herself as having a learning disability (i.e., developmental disability).

Of her children, she says: *"I love having kids. They're what keeps me going some days. When I feel the hardest on myself, especially about my disability, they're the ones that keep me going."*

When asked about her most recent pregnancy, Garima said she had an obstetrician and a midwife, whom she trusted. Due to negative experiences with the child welfare system as a teenager, and with her own children because of an abusive partner, she did not disclose her disability to her health care providers. However, she suspected they knew: *"I think they knew. I don't know how well they see previous records, but if they had happened to see my records before… I don't know, but with my child welfare worker I never told lies or anything."*

Garima had difficulty with her appetite during pregnancy. She had numerous ultrasounds, which she knew was not *"normal."* She felt her health care providers were not transparent with her about the reasons for the ultrasounds, but she was afraid to ask questions: *"I probably should have questioned it a bit more to understand why, but I didn't because I feel like if you ask too many questions, they might look at you weirdly."*

When Garima went into labour two weeks early, she was taken by ambulance to a different hospital than she had planned to deliver at. She was disappointed to not have the obstetrician and midwife that she trusted at her delivery. *"I didn't have my doctor, didn't have my OB. So it felt like I was alone."*

After the birth, Garima felt her health care team failed to clearly communicate important aspects of her newborn's care, including his low blood sugar. She said, *"They threatened to take him to the incubator and I'm like, 'What? What? Why? There's nothing wrong with him. Why? I don't understand this.' And they're like, 'Because of his sugar level.' I'm like, 'What do you mean by his sugar level?'" Garima had a difficult time understanding the way her health care providers talked to her as they used "doctor language."* However, she was afraid that if she asked more questions, her doctors would realize that she had a disability.

When asked what advice she would give to health care providers to make care better for people with developmental disabilities during pregnancy, Garima said, *"Stop talking doctor terms because not everyone's going to understand what 'hemorrhaging' is. I'll use that word for an example because not everyone knows what that means. I know what it means now but if I heard that five years ago, I'd probably be like, 'What? Huh? What?'"*

Based on an interview with a study participant. The name and details have been changed for privacy.

04

Labour and Birth Outcomes

MAIN MESSAGES

- **Labour and birth are a major transition in a person’s life, with health care in this period aimed at creating a positive experience while supporting health, preventing complications and responding to emergencies.**
- **We described labour and delivery interventions, birth outcomes, hospital length of stay, and breastfeeding initiation and support during the birth hospital stay among females with and without disabilities in Ontario.**
- **Females with disabilities in Ontario were generally no more likely than those without disabilities to experience labour and delivery interventions, but labour induction and Caesarean delivery were more common in those with multiple disabilities.**
- **Although relatively rare, newborns of females with developmental and multiple disabilities were more likely than those of females without disabilities to be born preterm, and newborns of females with developmental disabilities were more likely to be small for their gestational age.**
- **Females with developmental and multiple disabilities and their newborns had longer birth hospital stays than those without disabilities.**
- **Breastfeeding initiation and support during the birth hospital stay were generally high in all groups, but females with developmental and multiple disabilities experienced disparities in these outcomes.**
- **Care during the birth hospital stay should attend to the needs of birthing people with disabilities, especially those related to newborn care and breastfeeding, with careful post-discharge planning.**

Introduction

Labour and birth represent a major transition in a person's life. The goal of caring for individuals during labour and birth is to create a positive experience for them and their families, while supporting their health and that of their newborns, preventing complications, and addressing emergencies.[1,2] There are several characteristics of labour and birth that inform care during the birth hospital stay. Labour and delivery interventions, like Caesarean delivery, are intended to optimize the health of the birthing person or fetus when there are complications; however, these interventions are not without risk and signal the need for extra support during the birth hospital stay and careful post-discharge planning.[3] Likewise, birth characteristics such as preterm birth and size for gestational age reflect the support needs of the newborn.[4] Other broader factors, such as breastfeeding initiation and support during the birth hospital stay are important indicators of support received in hospital and are predictive of later breastfeeding success.[5] Currently, guidelines for the optimal care of people with disabilities during labour and birth are limited.[6,7]

To inform the development of high-quality labour and birth care for people with disabilities, the main questions this chapter will answer are:

- Are females with disabilities more likely than those without disabilities to experience labour and delivery interventions?
- Are newborns of females with disabilities more likely than those of females without disabilities to be born preterm or small for their gestational age?
- Do females with disabilities and their newborns have longer hospital stays than those without disabilities?
- Are females with disabilities less likely than those without disabilities to have opportunities for breastfeeding initiation and support during the birth hospital stay?

BACKGROUND

LABOUR AND DELIVERY INTERVENTIONS

A number of studies have examined labour and delivery interventions in people with disabilities. Our meta-analysis of prior studies showed higher Caesarean delivery rates in people with physical disabilities compared to those without disabilities.[8] Few studies have examined other labour and delivery interventions. One study using Washington State health administrative data found no difference in rates of labour induction or assisted vaginal delivery in d/Deaf versus hearing people.[9] Studies of surveys and health administrative data in the UK,[10,11] Sweden[12] and the US[13] also showed non-significant differences between groups. Labour and delivery intervention rates tend to vary by region,[3] so Ontario data on these outcomes are needed.

In this chapter, labour and delivery interventions are measured using three indicators. We report the proportion of 15 to 49-year-old females with physical, sensory, developmental and multiple disabilities, and without disabilities, with a birth in Ontario between 2010/11 and 2019/20 who experienced labour induction, assisted vaginal delivery and Caesarean delivery. For more details on how these labour and delivery interventions were measured, refer to the Technical Appendix.

Labour and delivery interventions
Labour and delivery interventions include labour induction, assisted vaginal delivery (i.e., use of forceps and/or vacuum extraction), and Caesarean delivery.

BIRTH OUTCOMES

Preterm birth is one of the most commonly examined outcomes among newborns of people with disabilities;[14] our prior meta-analysis demonstrated elevated risks in newborns of people with physical, sensory and developmental disabilities, compared to those of people without disabilities.[14] A smaller number of studies using health administrative data from the US have also shown elevated risk of small for gestational age in newborns of people with versus without disabilities.[9,15] However, Ontario population-based data on this topic are lacking.

In this chapter, we measure two indicators of birth outcomes. We report the proportion of 15 to 49-year-old females with physical, sensory, developmental and multiple disabilities, and without disabilities, with a birth in Ontario between 2010/11 and 2019/20 who had a preterm birth at less than 37 and less than 34 weeks gestation. We also report the proportions of births that were less than the 10th and the 3rd percentiles of birth weight for gestational age. For more details on how these birth outcomes were measured, refer to the Technical Appendix.

Birth outcomes
Gestational age and size for gestational age are both measured on a continuum, with thresholds defined to identify outcomes of different severities. In this Report, preterm birth is defined as birth at less than 37 and less than 34 weeks gestation. Small for gestational age is defined as birth weight less than the sex-specific 10th and the 3rd percentiles for that newborn's gestational age.[4]

BACKGROUND

LENGTH OF HOSPITAL STAY

Several studies have examined hospital length of stay in birthing people with disabilities, with different studies using different thresholds to define prolonged stays. For example, analyses of survey data in the UK showed stays of two or more[10] or three or more[16] days were more common in birthing people with disabilities than those without disabilities. Similar results were reported in studies of health administrative data in the US.[9,17,18] However, there are no Canadian studies on this topic.

In this chapter, length of hospital stay is measured relative to guidelines for birthing people and newborns in Canada.[23,24] We report the proportion of 15 to 49-year-old females with physical, sensory, developmental and multiple disabilities, and without disabilities, with a birth in Ontario between 2010/11 and 2019/20 who had a birth hospital stay of more than two days for vaginal births and more than three days for Caesarean births. We also report the proportion of newborns greater than 37 weeks gestation with a birth hospital stay of more than two days. For more details on how length of hospital stay was measured, refer to the Technical Appendix.

Length of hospital stay
Length of hospital stay for birthing people is defined separately for vaginal and Caesarean births, with prolonged stays defined as more than two days for vaginal births and more than three days for Caesarean births.[19] Prolonged stays for newborns greater than 37 weeks gestation is defined as more than two days.[20]

BREASTFEEDING INITIATION AND SUPPORT

There have been few quantitative studies examining breastfeeding in people with disabilities. A survey in the UK reported lower breastfeeding rates in the first few days postpartum in people with disabilities compared to those without disabilities.[16] In the US, linked survey and health administrative data showed fewer people with disabilities who recently gave birth reported ever breastfeeding or pumping, or current breastfeeding,[21] and that fewer people with developmental disabilities were breastfeeding at hospital discharge.[22] However, there are no Ontario population-based studies on this topic.

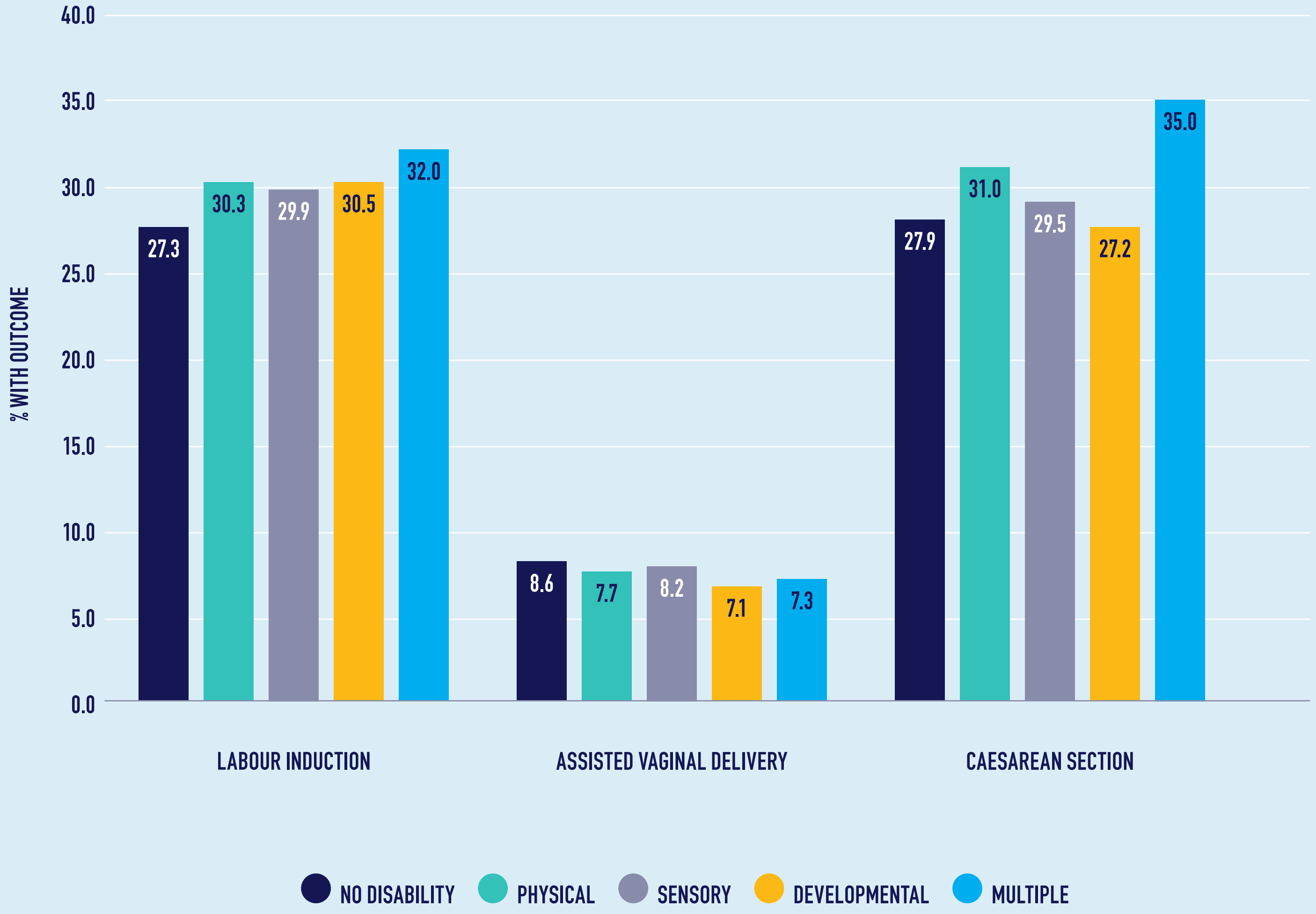
In this chapter, breastfeeding initiation and support are measured using four indicators.[23,24] For breastfeeding initiation, we report the proportion of 15 to 49-year-old females with physical, sensory, developmental and multiple disabilities, and without disabilities, with a livebirth in Ontario between 2012/13 and 2017/18 who had any breastfeeding and exclusive breastfeeding before discharge from the birth hospital stay. For breastfeeding support, we report the proportions who had skin-to-skin contact with the birthing parent within two hours of birth and provision of assistance with breastfeeding within six hours of birth. For more details on how breastfeeding initiation and support indicators were measured, refer to the Technical Appendix.

Breastfeeding initiation and support
Breastfeeding initiation and support are defined using four indicators from Baby Friendly Hospital Initiative guidelines developed by the World Health Organization and United Nations Children's Fund.[23] Breastfeeding initiation is defined as any breastfeeding and exclusive breastfeeding before discharge from the birth hospital stay. Breastfeeding support is defined as skin-to-skin contact with the birthing parent within two hours of birth and provision of assistance with breastfeeding within six hours of birth.

EXHIBITS AND FINDINGS

EXHIBIT 4.1

PREVALENCE OF LABOUR AND DELIVERY INTERVENTIONS AMONG 15 TO 49-YEAR-OLD FEMALES WITH AND WITHOUT DISABILITIES, IN ONTARIO, 2010/11–2019/20



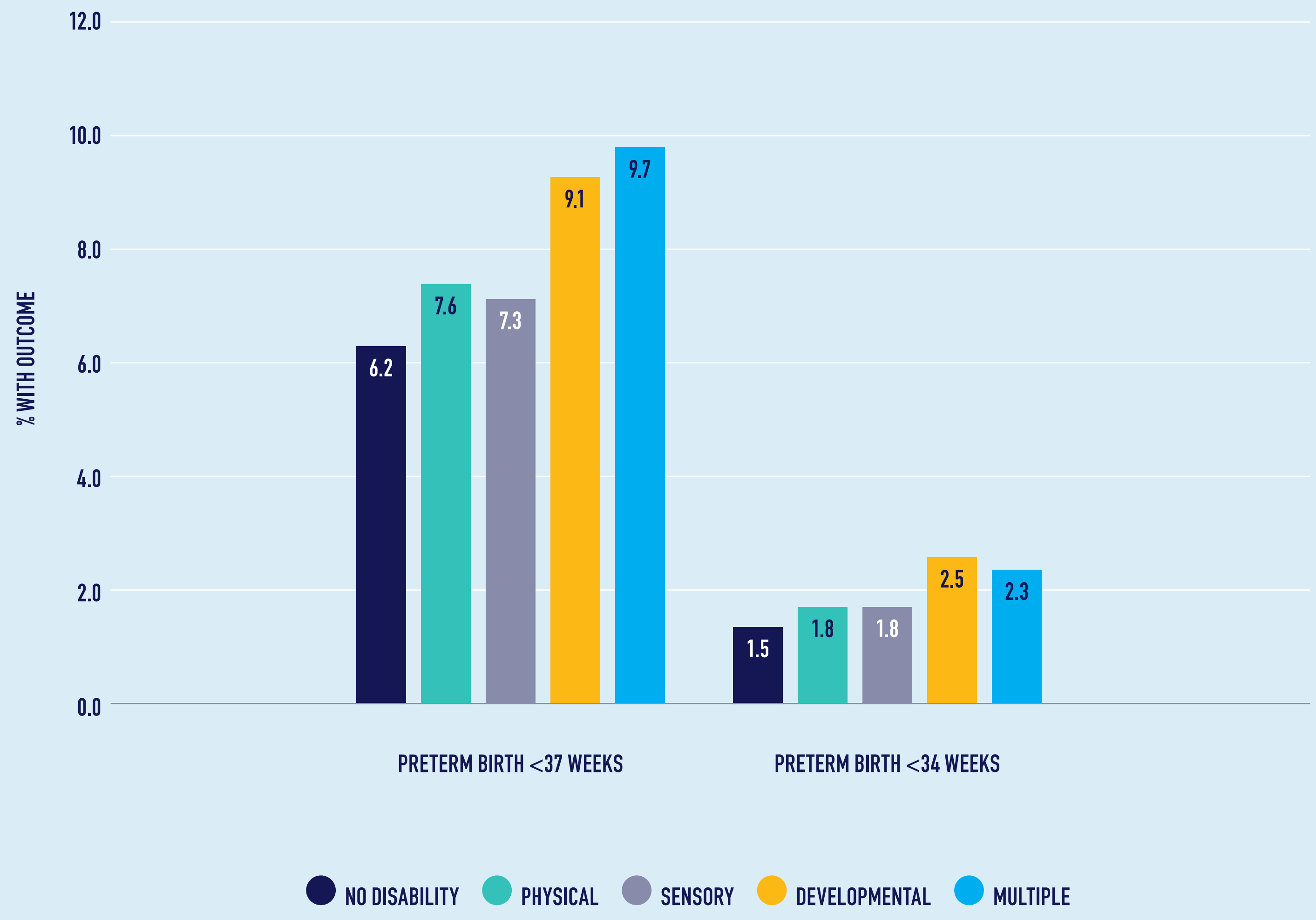
FINDINGS

- Labour and delivery interventions were common in females in Ontario overall.
- Labour induction was more common in females with multiple disabilities (32.0%) than in those without a disability (27.3%).
- Caesarean section was more common in females with multiple disabilities (35.0%) than in those without a disability (27.9%).

EXHIBITS AND FINDINGS

EXHIBIT 4.2

PREVALENCE OF PRETERM BIRTH AMONG 15 TO 49-YEAR-OLD FEMALES WITH AND WITHOUT DISABILITIES, IN ONTARIO, 2010/11–2019/20



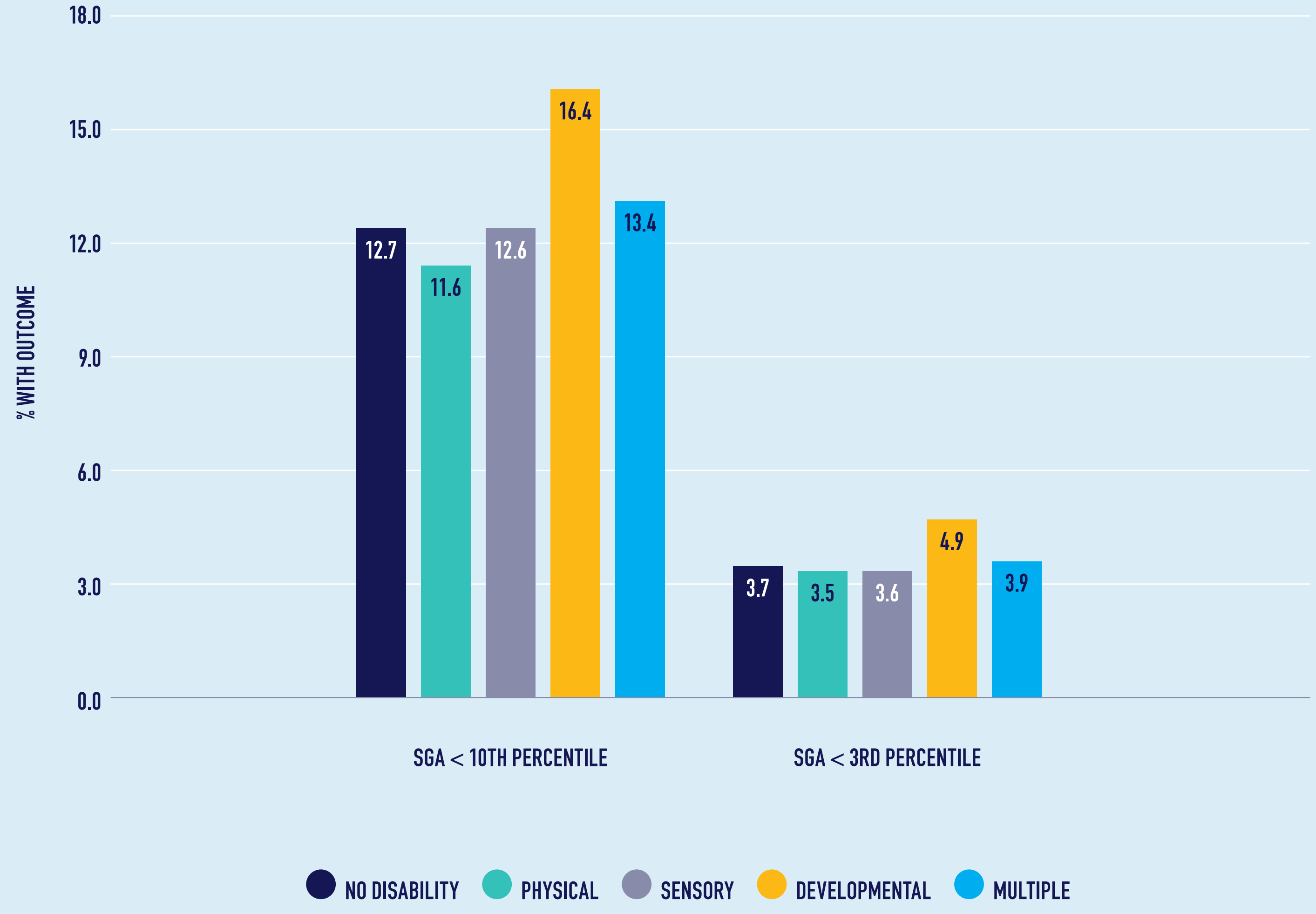
FINDINGS

- Newborns of females with developmental (9.1%) and multiple (9.7%) disabilities were more likely than newborns of females without a disability (6.2%) to be born at less than 37 weeks gestation.

EXHIBITS AND FINDINGS

EXHIBIT 4.3

PREVALENCE OF SMALL FOR GESTATIONAL AGE AMONG 15 TO 49-YEAR-OLD FEMALES WITH AND WITHOUT DISABILITIES, IN ONTARIO, 2010/11—2019/20



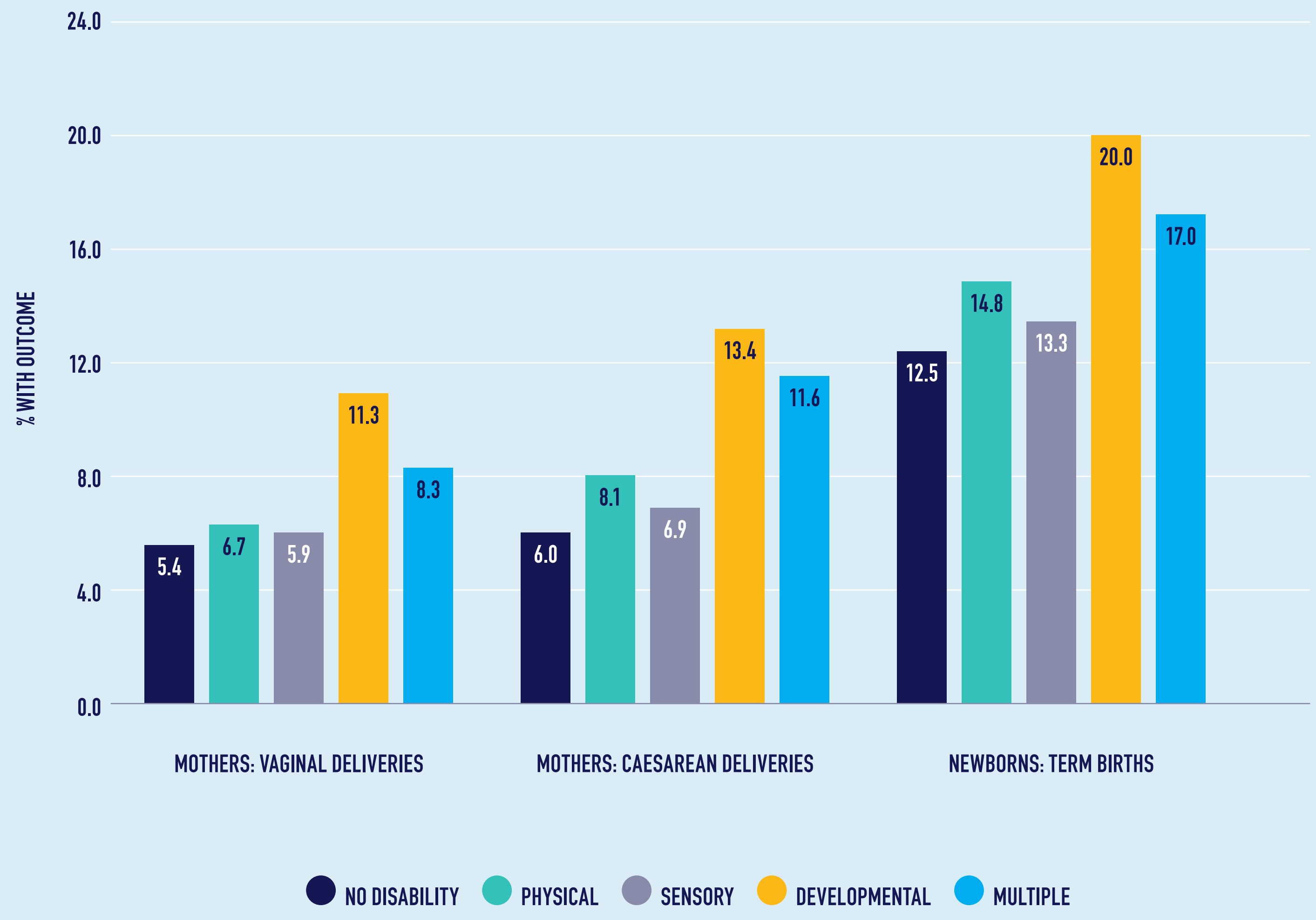
FINDINGS

- Newborns of females with developmental disabilities (16.4%) were more likely than newborns of females without a disability (12.7%) to be less than the 10th percentile of birth weight for their gestational age.

EXHIBITS AND FINDINGS

EXHIBIT 4.4

PREVALENCE OF PROLONGED BIRTH HOSPITAL STAYS AMONG 15 TO 49-YEAR-OLD FEMALES WITH AND WITHOUT DISABILITIES, AND THEIR TERM NEWBORNS, IN ONTARIO, 2010/11–2019/20



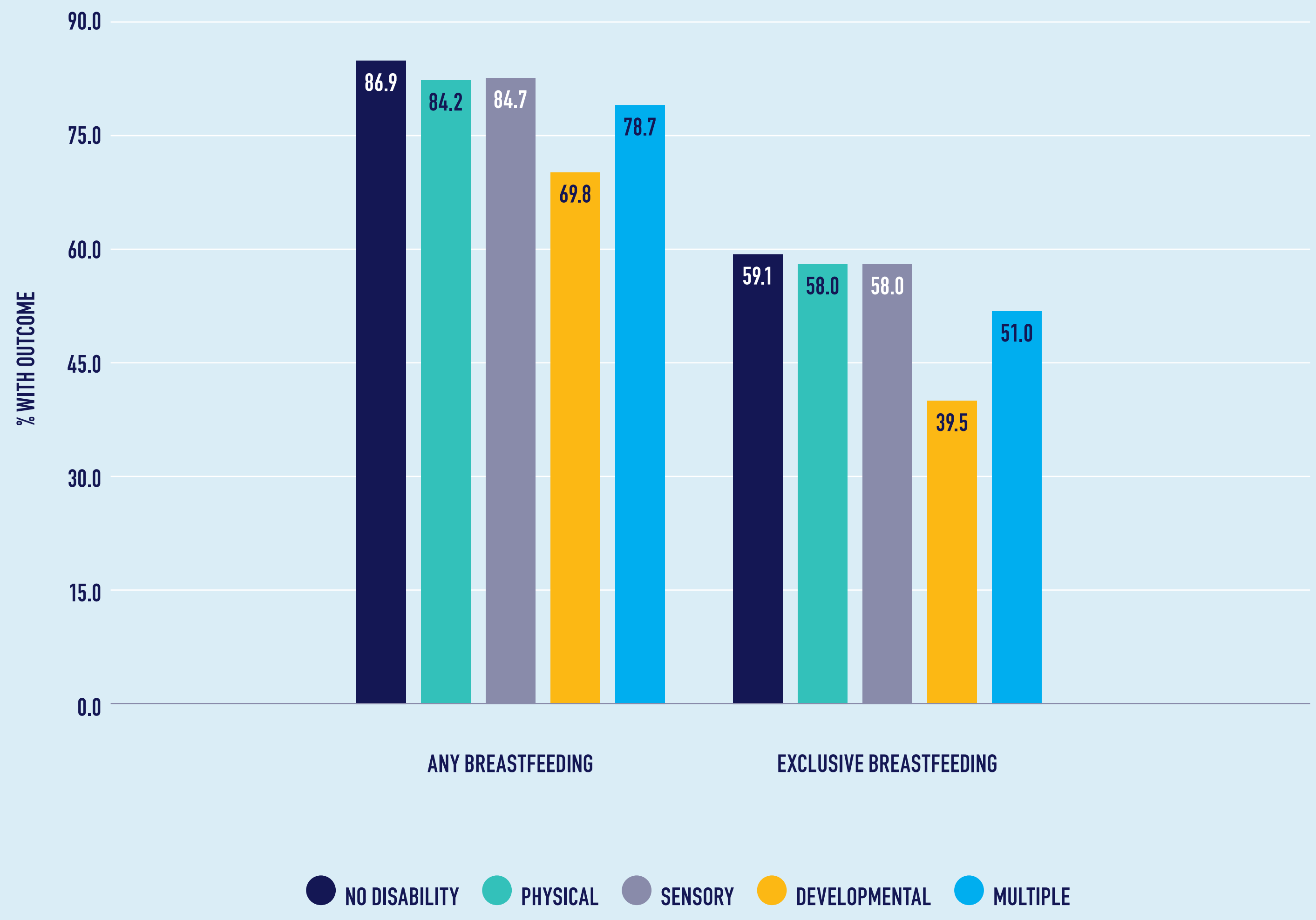
FINDINGS

- Among females with a vaginal delivery, those with developmental (11.3%) and multiple disabilities (8.3%) were more likely than females without a disability (5.4%) to have a birth hospital stay of more than two days.
- Among females with a Caesarean delivery, those with developmental (13.4%) and multiple disabilities (11.6%) were more likely than females without a disability (6.0%) to have a birth hospital stay of more than three days.
- Term newborns of females with developmental (20.0%) and multiple disabilities (17.0%) were more likely than those of females without a disability (12.5%) to have a birth hospital stay of more than two days.

EXHIBITS AND FINDINGS

EXHIBIT 4.5

BREASTFEEDING INITIATION AMONG 15 TO 49-YEAR-OLD FEMALES WITH AND WITHOUT DISABILITIES, IN ONTARIO, 2012/13–2017/18



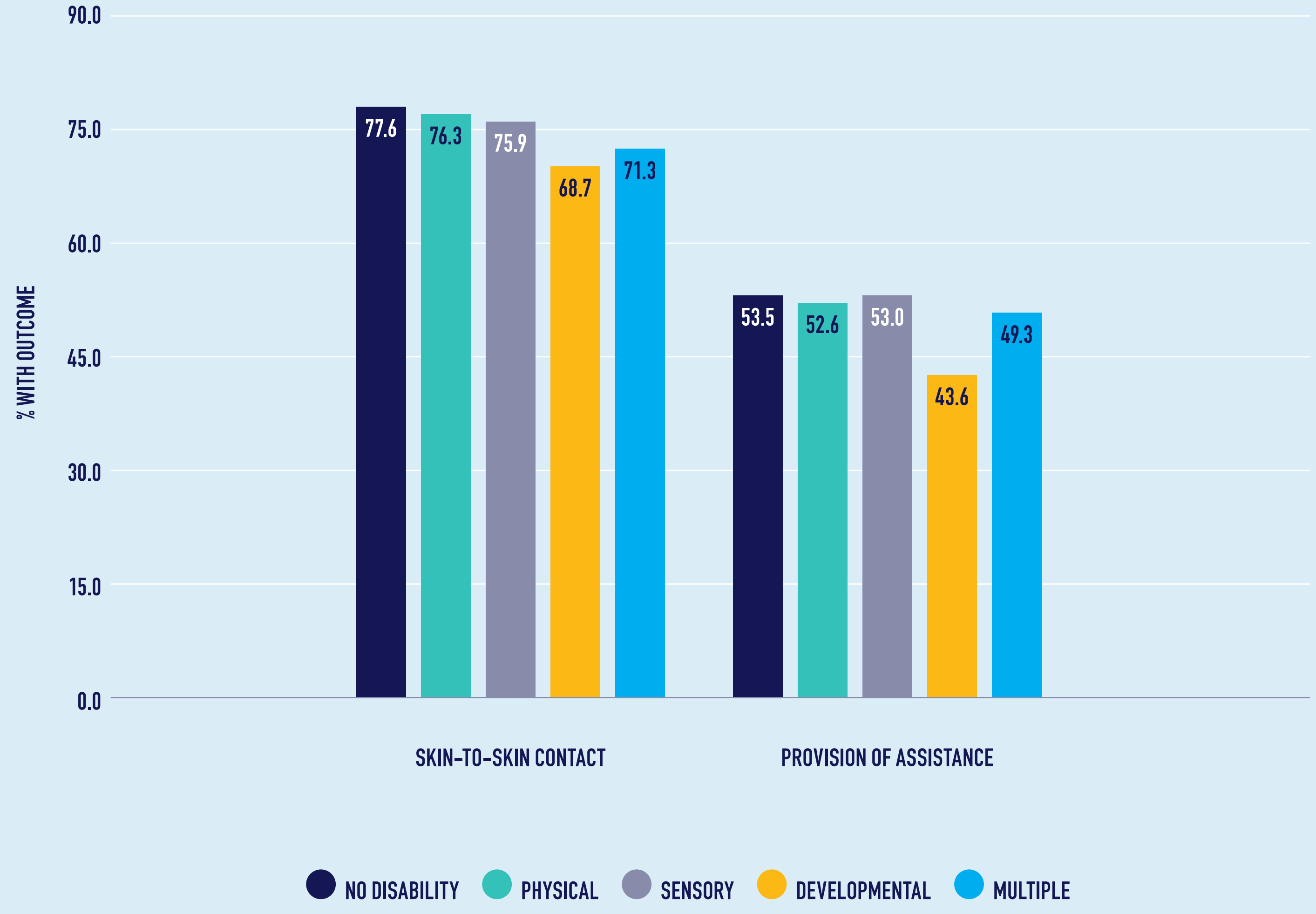
FINDINGS

- Most females in Ontario had some breastfeeding during the birth hospital stay.
- Females with developmental (69.8%) and multiple disabilities (78.7%) were less likely than those without a disability (86.9%) to have some breastfeeding during the birth hospital stay.
- Females with developmental (39.5%) and multiple disabilities (51.0%) were less likely than those without a disability (59.1%) to exclusively breastfeed during the birth hospital stay.

EXHIBITS AND FINDINGS

EXHIBIT 4.6

RECEIPT OF BREASTFEEDING SUPPORT AMONG 15 TO 49-YEAR-OLD FEMALES WITH AND WITHOUT DISABILITIES, IN ONTARIO, 2012/13–2017/18



FINDINGS

- Females with developmental (68.7%) and multiple disabilities (71.3%) were less likely than those without a disability (77.6%) to have skin-to-skin contact with their baby within two hours after childbirth.
- Females with developmental disabilities (43.6%) were less likely than those without a disability (53.5%) to be provided with assistance with breastfeeding within six hours of birth.

DISCUSSION

LABOUR AND DELIVERY INTERVENTIONS

There are few differences in rates of labour and delivery interventions in females with and without disabilities in Ontario, with only rates of labour induction and Caesarean delivery being elevated in those with multiple disabilities. Our prior meta-analysis showed elevated rates of Caesarean delivery in people with physical but not in sensory or developmental disabilities.[8] Among the few studies that reported on labour induction and assisted vaginal delivery, findings across disability groups were mixed.[9-13] Differences across prior studies and this Report might be due to regional variations in intervention rates, or those of studies' disability definitions.

Higher rates of Caesarean delivery in people with multiple disabilities might be attributable to medical need, including complications impacting the birthing person or fetus and necessitating intervention. However, prior studies have also suggested that people with disabilities might be less likely to be given an opportunity to labour, with providers assuming the necessity of Caesarean delivery even in the absence of medical complications.[9] Further research is needed to fully understand the drivers of the findings we observed.

BIRTH OUTCOMES

Preterm birth is more common in newborns of females with developmental and multiple disabilities in Ontario compared to those without disabilities, while small for gestational age is more common in newborns of females with developmental disabilities. These findings are consistent with prior studies,[9,14,15] although differences in these outcomes for people with physical and sensory disabilities were smaller than previously reported.[14] Again, variations in findings may be due to differences across health care systems and studies' disability definitions.

Higher rates of preterm birth and small for gestational age in newborns of people with developmental and multiple disabilities might relate to a combination of social and structural determinants of health, such as poverty, and medical factors, such as underlying chronic conditions and medication use in pregnant people with disabilities.[14]

LENGTH OF HOSPITAL STAY

Females with developmental and multiple disabilities and their newborns in Ontario have longer birth hospital stays than females without disabilities. Prior studies have used different definitions of "prolonged stay" but have mostly shown that people with disabilities and their newborns stay in hospital longer after birth.[9,10,16-18]

Reasons for prolonged hospital stays for birthing parents with disabilities and their newborns might reflect elevated medical needs, including higher rates of serious physical health complications and preterm birth, for example, particularly in people with developmental and multiple disabilities. However, longer hospital stays might also reflect the need for time to organize post-discharge supports for these groups.[19,20]

BREASTFEEDING INITIATION AND SUPPORT

Most females in Ontario have opportunities for breastfeeding initiation and support during the birth hospital stay. However, females with developmental and multiple disabilities are less likely than those without disabilities to initiate breastfeeding and receive breastfeeding supports. These findings are generally consistent with prior studies,[16,21,22] though, unlike prior studies, we did not observe differences for females with physical disabilities.

Lower rates of breastfeeding initiation and support during the birth hospital stay in people with developmental and multiple disabilities may be partly due to health care provider assumptions about disabled parents' ability to breastfeed or contraindications for breastfeeding such as medication use. Other possible factors include elevated rates of parental[8] and newborn[14] health complications, or child welfare involvement, that might result in separation of parents and newborns during the birth hospital stay.[25]

DISCUSSION

IMPLICATIONS FOR POLICY AND PRACTICE

Ensure access to disability-related accommodations during the birth hospital stay

Findings of elevated rates of labour and delivery interventions, birth complications, and longer birth hospital stays among people with disabilities and their newborns, and particularly people with multiple disabilities, show the need for ongoing access to disability-related accommodations and services during birth hospital stays. In our interviews, this was particularly an issue for participants who were d/Deaf. For example, Shannon shared:

"I only had the interpreter for the delivery and then that was it... And the nurses come, they come in a lot when you're in the hospital. They're doing bloodwork and there was no interpreter for that... As long as the patient's in the hospital, they should have someone on hand from 8am to 5pm, at least. So that the nurses can interact and if they have questions, they can talk to the nurse."

Provide information to facilitate shared decision-making about labour and delivery

Despite the absence of meaningful differences in labour and delivery interventions between people with and without disabilities in our cohort, people with disabilities should have access to the information they need to make an informed decision about their labour and delivery options. Although not possible to measure in health administrative data, lack of autonomy and shared decision-making about their delivery mode was an issue raised by many people with disabilities in our interviews. For example, Miriam, who has multiple sclerosis, shared:

"For me, what keeps coming up is the lack of options and choices... A vaginal birth wasn't even a consideration. Like it just was not part of the conversations, that it was important to me to have a vaginal birth because I wanted to be sure that we had a healthy start for breastfeeding and not having the surgical intervention. I mean, choice is not a 'yes' or 'no'; there's a spectrum and there's all these kinds of issues that come into play for people in terms of what choices are available to them but also the importance of why those choices need to be available... And that just wasn't on anybody's radar."

Other participants described occasions where they were provided with adequate information about their labour and delivery options. This was often in the context of multidisciplinary, patient-centred care. For example, Johanna, who has muscular dystrophy and osteoporosis, said:

"So then there was a care plan meeting organized, where everybody involved in my care like the nurses, my doctor, the anesthesiologist, the neurologist, everybody who was going to come together for this one meeting and then my husband and I would be there and we'd be able to express what we were worried about and then we'd be able to stamp out the plan."

This careful planning is especially critical in the context of labour specifically when patients may be under anesthetic and unable to advocate for themselves.

Johanna further explained:

"I was really concerned about the day of delivery and the transfer, things like that. I also have, like just because I don't move, I have osteoporosis and really bad contractures and I can't lay flat on my back, and I was just picturing everybody putting me under and then just fracturing me because they didn't understand my body... So, what we decided to do was that in the morning, I would go on the stretcher, and they would do whatever they need to do, IVs and stuff like that. And then they were going to take me and transfer me to the surgical bed, but my husband was allowed to be in for that. And then, my doctor wanted me to get in a position where I was comfortable using pillows and things like that. And then, once that was done, then they put me under. So, when I woke up, it was good. There was no broken bones."

DISCUSSION

Develop accessible breastfeeding supports

Our findings also reflect the need for more accessible breastfeeding supports for people with disabilities during the birth hospital stay. Although we only observed small differences in the provision of breastfeeding supports between groups, many participants in our interviews, particularly d/Deaf and blind participants, noted that breastfeeding resources did not take into account their disability, and that providers were inflexible in their advice. Siobhan, who is blind, recounted:

> ***"When you're in the hospital and they're teaching you how to breastfeed, they do this thing where they hold the baby, they wait until the baby's mouth is open, and then they fly it on when they think it's the right moment. And that doesn't teach the blind person how to breastfeed at all. That makes the blind person totally dependent on having the nurse there to watch when the baby's mouth is open."***

Plan for supports after discharge

Finally, findings of elevated risks of Caesarean delivery, preterm birth, and small for gestational age birth, particularly in people with developmental and multiple disabilities, show the importance of careful post-discharge planning to ensure people with disabilities have the supports they need when they return home, to address the medical needs of the birthing person and their newborn and reduce the risk of hospital readmission. However, many of the people we interviewed identified a lack of post-discharge supports. For example, Alyssa, who has cerebral palsy, described feeling like she was not adequately prepared to manage her recovery from a Caesarean delivery:

> ***"There wasn't a lot [of physical care]. They mostly just said change the dressing every day, and they said it was okay to get it wet as long as you just pat it dry. When I was sent home, pretty quickly there was more discharge and bleeding from the incision than usual. So, I went to my obstetrician and the nurse was just appalled that they would even send me home at all with my incision in that condition."***

DISCUSSION

DATA NEEDS

Several data limitations should be considered when interpreting our findings:

- While we were able to measure events that occurred during the birth hospital stay, we could not determine how those events were experienced by birthing people or their health care providers. The pregnancy care experiences of people with disabilities are explored in more depth in Chapter 6.
- We had no information on births outside of hospital settings (e.g., those occurring at home or in midwifery-run birth centres). However, hospital births represent 98% of all births in Ontario.[26]
- We were unable to measure indications for different labour- and birth-related events, such as Caesarean delivery and hospital length of stay. These indications may differ for people with and without disabilities.
- In this chapter and others, we did not examine outcomes according to specific types of disabilities (e.g., spinal cord injuries or cerebral palsy). This may mean that some heterogeneity in outcomes, such as Caesarean delivery, might be masked due to this “high level” view of disability.

FUTURE RESEARCH

There are several avenues for future research that could help to inform policy and clinical practice related to labour and birth for people with disabilities, including:

- Studies on factors that contribute to higher rates of preterm birth and small for gestational age among newborns of people with developmental and multiple disabilities;
- Studies on reasons for longer birth hospital stays in people with developmental disabilities and their newborns; and
- Studies on factors that contribute to lower rates of breastfeeding initiation and support among people with developmental and multiple disabilities.

Such studies should consider factors at the system, provider and patient levels. The results of this additional research could be used to help identify new areas where we need to improve the labour and birth-related care of people with disabilities to better meet their needs.

Conclusion

This chapter shows that females with disabilities are generally no more likely than those without disabilities to experience labour and delivery interventions, though labour induction and Caesarean delivery are more common in females with multiple disabilities. Newborns of females with developmental and multiple disabilities are more likely to be born preterm, and newborns of females with developmental disabilities are more likely to be small for their gestational age. Females with developmental and multiple disabilities and their newborns have longer birth hospital stays. Breastfeeding initiation and support during the birth hospital stay are high across groups, but females with developmental and multiple disabilities experience important disparities in these indicators. Care during the birth hospital stay should attend to the needs of birthing people with disabilities, especially those related to newborn care and breastfeeding, with careful post-discharge planning.

Related publications

- Brown HK, Chen S, Guttmann A, Havercamp S, Parish S, Ray JG, et al. Neonatal outcomes of mothers with a disability. *Pediatrics* 2022; 150(3):e2021055318.
- Brown HK, Taylor C, Vigod SN, Dennis CL, Fung K, Chen S, et al. Disability and in-hospital breastfeeding practices and support: a population-based study. *Lancet Public Health* 2023; 8(1):E47–56.
- Kassee C, Lunsky Y, Patrikar A, Brown HK. Impact of social-, health-, and disability-related factors on pregnancy outcomes in women with intellectual and developmental disabilities: a population-based latent class analysis. *Disabil Health J* 2023; 6(2):101426.

RETURN TO PREVIOUS PAGE

References

1. Public Health Agency of Canada. *Family-Centred Maternity and Newborn Care: National Guidelines.* Ottawa: PHAC; 2017.
2. Society of Obstetricians and Gynaecologists of Canada. Joint policy statement on normal childbirth. *J Obstet Gynaecol Can* 2008; 30(12):1163–5.
3. Sandall J, Tribe RM, Avery L, Mola G, Visser GHA, Homer CSE, et al. Short-term and long-term effects of caesarean sections on the health of women and children. *Lancet* 2018; 392(10155):1349–57.
4. Irvine B, Dzakpasu S, Leon JA. Perinatal health indicators 2013: a surveillance report by the Public Health Agency of Canada's Perinatal Surveillance System. *Health Promot Chronic Dis Prev Can* 2015; 35(1):23–4.
5. Karimi A, Talat K, Swpideh B. Effect of immediate and continuous mother–infant skin-to-skin contact on breastfeeding self-efficacy of primiparous women: a randomised control trial. *Women Birth* 2014; 27(1):37–40.
6. Berndl A, Ladhani N, Wilson RD, Basso M, Jung E, Tarasoff LA, et al. Guideline No. 416: labour, delivery, and postpartum care for people with physical disabilities. *J Obstet Gynaecol Can* 2021; 43(6):769–80.
7. Sullivan WF, Diepstra H, Heng J, Ally S, Bradley E, Casson I, et al. Primary care of adults with intellectual and developmental disabilities: 2018 Canadian consensus guidelines. *Can Fam Physician* 2018; 64(4):254–79.
8. Tarasoff LA, Ravindran S, Malik H, Salaeva D, Brown HK. Maternal disability and risk for pregnancy, delivery, and postpartum complications: a systematic review and meta-analysis. *Am J Obstet Gynecol* 2020; 222(1):27.e1–27.e32.
9. Schiff MA, Doody DR, Crane DA, Mueller BA. Pregnancy outcomes among deaf women in Washington State, 1987–2012. *Obstet Gynecol* 2017; 130:953–60.
10. Malouf R, Henderson J, Redshaw M. Access and quality of maternity care for disabled women during pregnancy, birth and the postnatal period in England: data from a national survey. *BMJ Open* 2017; 7:e016757.
11. Goldacre A, Gray R, Goldacre M. Childbirth in women with intellectual disability: characteristics of their pregnancies and outcomes in an archived epidemiological dataset. *J Intellect Disabil Res* 2015; 59:1653–63.
12. Höglund B, Lindgren P, Larsson M. Pregnancy and birth outcomes of women with intellectual disability in Sweden: a national register study. *Acta Obstet Gynecol Scand* 2012; 91:1381–7.
13. Mwachofi AK. A comparative analysis of pregnancy outcomes for women with and without disabilities. *J Health Disparities Res Pract* 2017; 10(1):28.
14. Tarasoff L, Murtaza F, Salaeva D, Carty A, Hamilton A, Brown HK. Health of newborns and infants born to women with disabilities: a systematic review and meta-analysis. *Pediatrics* 2020; 146(6):e20201635.
15. Mitra M, McKee MM, Akobirshoev I, et al. Pregnancy, birth, and infant outcomes among women who are deaf or hard of hearing. *Am J Prev Med* 2020; 58(3):418–26.
16. Redshaw M, Malouf R, Gao H, Gray R. Women with disability: the experience of maternity care during pregnancy, labour and birth and the postnatal period. *BMC Pregnancy Childbirth* 2013;13(1): 1.
17. Horner-Johnson W, Darney G, Biel FM, Caughey AB. Prolonged postpartum length of hospital stay among women with disabilities. *Disabil Health J* 2020; 13(4):100934.
18. Mueller BA, Crane D, Doody DR, Stuart SN, Schiff MA. Pregnancy course, infant outcomes, rehospitalization, and mortality among women with intellectual disability. *Disabil Health J* 2019; 12(3):452–9.
19. Cargill Y, Martel MJ and the Clinical Practice Obstetrics Committee. Postpartum maternal and newborn discharge. *J Obstet Gynaecol Can* 2007; 190:357–9.
20. Lemyre B, Jefferies AL, O'Flaherty P. *Facilitating discharge from hospital of the healthy term infant.* Ottawa (ON): Canadian Paediatric Society; 2018.
21. Mitra M, Clements KM, Zhang J, Iezzoni LI, Smeltzer SC, Long-Bellil LM. Maternal characteristics, pregnancy complications, and adverse birth outcomes among women with disabilities. *Med Care* 2015; 53(12):1027–32.
22. Mitra M, Parish SL, Clements KM, Cui X, Diop H. Pregnancy outcomes among women with intellectual and developmental disabilities. *Am J Prev Med* 2015; 48(3):300–8.
23. World Health Organization. *Protecting, promoting and supporting breastfeeding in facilities providing maternity and newborn services: the revised Baby-Friendly Hospital Initiative.* Geneva: World Health Organization; 2018.
24. Taylor CL, Brown HK, Saunders NR, Barker LC, Chen S, Cohen E, et al. Maternal schizophrenia, skin-to-skin contact, and infant feeding initiation. *Schizophr Bull* 2022; 48(1):145–53.
25. Powell R, Mitra M, Smeltzer SC, Long-Bellil LM, Smith LD, Rosenthal E, et al. Breastfeeding among women with physical disabilities in the United States. *J Hum Lact* 2018; 34(2):253–61.
26. Statistics Canada. *Live births and fetal deaths (stillbirths) by place of birth (hospital or non-hospital), Canada, provinces and territories, annual, 2021.* Ottawa: Statistics Canada; 2021. Accessed July 26, 2021. https://www150.statcan.gc.ca/t1/tbl1/en/tv.action?pid=1310042901.

MACKENZIE is a Deaf woman who lives with her husband and children in a mid-sized town. Mackenzie's most recent pregnancy was with twins.

Her obstetrician was a great advocate for her disability-related needs. *"The doctor that I got was great for a deaf patient. That doctor got what I needed and what d/Deaf patients needed. The first appointment with them, they got an interpreter."* When there was no interpreter at a follow-up appointment, the doctor informed the receptionist that it was Mackenzie's right to have an interpreter present at her appointments and the issue was resolved for subsequent appointments.

Mackenzie delivered her twins by Caesarean section. She described how there was an interpreter present leading up to the delivery but not during the delivery: *"The interpreter was there for all of that, but then they sent her home. And then an hour after they sent her home, they had decided it was time to do the Caesarean section… and there was another interpreter, but they were on holidays."* Once the babies were delivered, the interpreter came back; however, Mackenzie stressed the importance of needing an interpreter continuously during the birth and hospital stay in case something went wrong during or after delivery.

After her twins were born, Mackenzie's son was slow to gain weight due to a tongue tie. She said, *"The feeding team for him [at the hospital] were great; they were bringing in interpreters, it was so good."* However, Mackenzie again experienced gaps in the provision of interpreters during the newborn phase, which made understanding their physician's instructions extremely difficult: *"The paediatrician, she refused to get interpreters, and she would get mad with us because we were screwing up the formula measurements… And they were asking 'Why are you getting the formula mixed up?', and I was like 'Because the paediatrician's not getting an interpreter.' So, finally I think, I forget when exactly, but they finally brought in an interpreter. And then things got better with the formula and everything when he was about five months old."*

When asked what advice she would give to health care providers to improve pregnancy care for d/Deaf people, Mackenzie said, *"Get an interpreter from the get go, because it's for them; the interpreter's for them, not for me. It's like when they notice during the gestation or during pregnancy if a baby has a heart problem, they bring in a cardiologist to focus on that problem. So the interpreter's the same thing."*

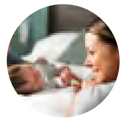
Based on an interview with a study participant. The name and details have been changed for privacy.

05

Postpartum and Newborn Outcomes

MAIN MESSAGES

- **The postpartum period is a time of significant change related to physical recovery from childbirth and elevated psychological stress due to fatigue and new infant care responsibilities.**
- **To gain a better understanding of the postpartum care needs of people with disabilities, we described outpatient postpartum care access; emergency department visits and hospital admissions; and the physical health, mental health and experiences of interpersonal violence in the postpartum period of females with and without disabilities in Ontario, along with the health care needs of their newborns.**
- **Most females in Ontario received a standard postpartum outpatient visit at six weeks after childbirth.**
- **Females with disabilities were more likely than those without disabilities to have emergency department visits and hospital admissions in the postpartum period.**
- **Females with disabilities were also more likely than those without disabilities to experience rare but serious physical health complications, mental health conditions and interpersonal violence in the postpartum period.**
- **Though rare, newborns of females with developmental and multiple disabilities were more likely than newborns of those without disabilities to have a neonatal intensive care unit admission.**
- **Coordinated, multidisciplinary care across the extended postpartum period that is responsive to the needs of people with disabilities and their newborns is required.**



Introduction

The postpartum period is a time of significant change related to physical recovery from childbirth and elevated psychological stress due to fatigue and new infant care responsibilities. The focus of postpartum care typically shifts rapidly from the postpartum person to the infant, with most Canadians receiving outpatient postpartum care from a physician at a single routine visit at six weeks after childbirth.[1] Late or missed outpatient postpartum visits, along with postpartum hospital care, signal that more could be done to support postpartum people with high-quality outpatient care to avoid preventable complications.[2,3] Similarly, measures of physical health, mental health and other needs of postpartum people are important for informing the structure and content of postpartum care. As in pregnancy, rates of serious physical health complications in the postpartum period reflect a need for more frequent and longer postpartum visits to monitor patients' health. Likewise, postpartum mental illness and exposure to interpersonal violence demonstrate the need for specialized supports.[4] Supporting the postpartum person is intimately intertwined with supporting the newborn;[5] therefore, indicators of elevated health care needs in newborns are also informative for the types of resources postpartum people need. Similar to care related to pregnancy and labour and birth, guidelines for the optimal postpartum care of disabled people are limited.[6,7]

To inform the development of high-quality postpartum care for people with disabilities, the main questions this chapter will answer are:

- How does outpatient postpartum care access in females with disabilities compare to those without disabilities?
- Are females with disabilities more likely than those without disabilities to have emergency department visits and hospital admissions in the postpartum period?
- Are females with disabilities more likely than those without disabilities to experience serious physical health complications, mental health conditions and interpersonal violence in the postpartum period?
- Are newborns of females with disabilities more likely than those of females without disabilities to require neonatal intensive care unit admission in the first 28 days of life?

BACKGROUND

ACCESS TO OUTPATIENT POSTPARTUM CARE

Few quantitative studies have examined outpatient postpartum care access among people with disabilities. One study in the US using health administrative data showed no difference in routine postpartum visit receipt in people with developmental disabilities versus those without developmental disabilities.[8] Similarly, a survey in the UK showed people with disabilities had similar rates of routine postpartum visits as those without disabilities.[9] However, surveys may exclude those who are most under-served. Population-based data within Ontario's universal health care system are thus useful for studying outpatient postpartum care access.

In this chapter, we measure access to postpartum care by reporting the proportion of 15 to 49-year-old females with physical, sensory, developmental and multiple disabilities, and without disabilities, with a birth in Ontario between 2010/11 and 2019/20, who had a routine six-week postpartum outpatient visit, as recommended.[1] For more details on how postpartum care access was measured, refer to the Technical Appendix.

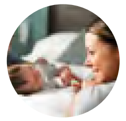
Postpartum care access
Postpartum care access is defined by the receipt of a six-week postpartum visit with a general practitioner or obstetrician for the purposes of health promotion and disease prevention, aligned with Society of Obstetricians and Gynaecologists of Canada guidelines.[1]

EMERGENCY DEPARTMENT VISITS AND HOSPITAL ADMISSIONS IN THE POSTPARTUM PERIOD

Several quantitative studies have examined hospital care in people with disabilities in the postpartum period. For example, a study of Medicaid recipients in the US found people with disabilities were more likely than those without disabilities to be re-hospitalized within three months of delivery.[10] Another study in the US using linked survey and health administrative data found people with developmental disabilities had elevated risks of postpartum emergency department visits and hospital admissions within 365 days.[11] In contrast, two studies of Washington State health administrative data found no increased risk for hospitalization for people with developmental disabilities or vision loss within two years of childbirth.[12,13] Ontario data are needed to understand hospital care patterns in postpartum people with disabilities in the context of our universal health care system.

In this chapter, we measured postpartum emergency department visits and hospital admissions. For these indicators, we report the proportion of 15 to 49-year-old females with physical, sensory, developmental and multiple disabilities, and without disabilities, with a birth in Ontario between 2010/11 and 2019/20, who had an emergency department visit or hospital admission, overall and for obstetric, other medical and psychiatric reasons, between birth hospitalization discharge and 365 days thereafter.
For more details on how postpartum emergency department visits and hospital admissions were measured, refer to the Technical Appendix.

Emergency department visits and hospital admissions in the postpartum period
Emergency department visits are unscheduled visits by patients who may need immediate care in facilities staffed by physicians around the clock, seven days per week. Hospital admissions are planned and unplanned inpatient hospital stays. These are further defined according to the diagnosis used to describe the primary reason for the encounter, as being for obstetric, other medical or psychiatric reasons.



BACKGROUND

PHYSICAL HEALTH, MENTAL HEALTH AND OTHER NEEDS IN THE POSTPARTUM PERIOD

Only a handful of quantitative studies have examined the physical health of disabled people in the postpartum period. Three studies using health administrative data in the US showed elevated risk of serious physical health complications (e.g., hemorrhage) in people with disabilities compared to those without disabilities; however, follow-up was limited to the immediate postpartum period.[14-16] Data on other needs are also required. For example, surveys in the US suggest people with disabilities are at elevated risk for symptoms of postpartum depression.[17,18] Further, while existing studies also suggest people with disabilities are at elevated risk of interpersonal violence in pregnancy, the postpartum period has not been examined.[19,20] Data on these outcomes are needed to inform the content and structure of postpartum care for people with disabilities.

In this chapter, we measure indicators of postpartum physical health, mental health and interpersonal violence. First, we report the proportion of 15 to 49-year-old females with physical, sensory, developmental and multiple disabilities, and without disabilities, with a birth in Ontario between 2010/11 and 2019/20, who experienced a serious physical health complication (e.g., hemorrhage, sepsis, intensive care unit admission or death) within 0 to 42 and 43 to 365 days of childbirth.[21] Second, we report the proportion who had a health care encounter for a mood or anxiety, psychotic, substance use or other mental disorder, or self-harm within 365 days. Third, we report the proportion who experienced an emergency department visit for interpersonal violence within 365 days.[22] For more details on how these indicators were measured, refer to the Technical Appendix.

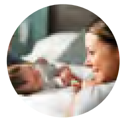
Physical health, mental health and interpersonal violence in the postpartum period
Physical health is defined by the occurrence of serious complications (e.g., hemorrhage, sepsis, intensive care unit admission or death) from 0 to 42 days and 43 to 365 days after childbirth.[21] Mental health is defined by physician visits, emergency department visits and hospital admissions for a mood or anxiety, psychotic, substance use or other mental disorder, and emergency department visits for self-harm within 365 days of childbirth. Interpersonal violence is defined as an emergency department visit for assault or other maltreatment within 365 days of childbirth.[22]

NEWBORN HEALTH CARE NEEDS

Supporting the postpartum person is intimately intertwined with supporting the newborn; therefore, indicators of elevated health care needs among newborns are also informative for the types of resources postpartum people need. Several quantitative studies have examined indicators of health care needs among newborns of people with disabilities, including neonatal intensive care unit admission. Our prior meta-analysis showed increased risk of neonatal intensive care unit admission in newborns of people with developmental disabilities.[23] Similar risks have been found in newborns of people with any disability,[24] and with vision loss,[25] using linked survey and health administrative data from the US. A cross-disability comparison using Ontario population-based data is therefore warranted to identify the needs of new parents with disabilities and their newborns.

In this chapter, we report the proportion of newborns of 15 to 49-year-old females with physical, sensory, developmental and multiple disabilities, and without disabilities, in Ontario between 2010/11 and 2019/20, who were admitted to the neonatal intensive care unit within 28 days of birth. For more details on how neonatal intensive care unit admission was measured, refer to the Technical Appendix.

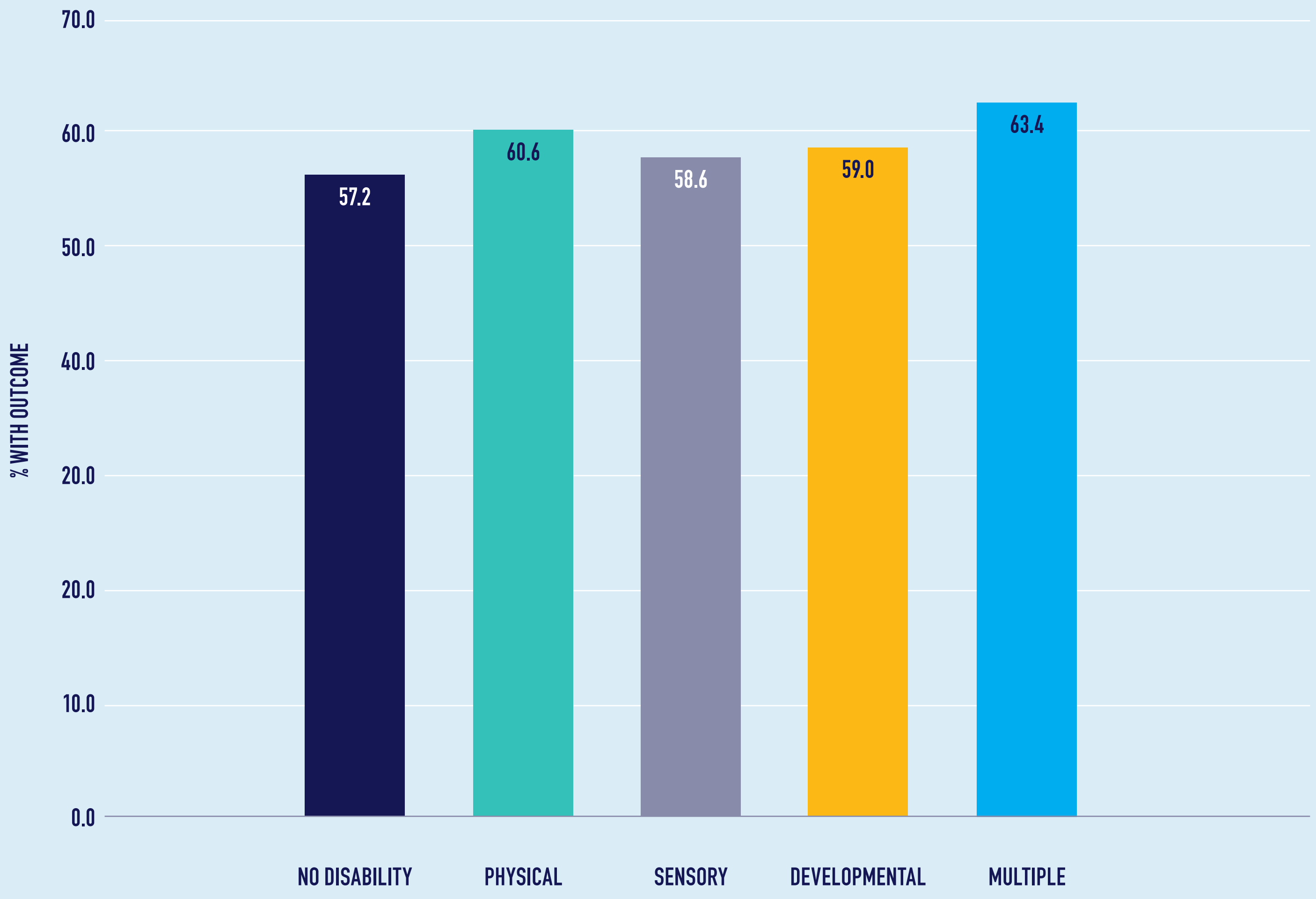
Newborn health care needs
Newborn health care needs are defined by an overall indicator of admission to an intensive care unit, or equivalent, during the birth hospital admission or within 28 days of birth.



EXHIBITS AND FINDINGS

EXHIBIT 5.1

RECEIPT OF A ROUTINE SIX-WEEK POSTPARTUM OUTPATIENT VISIT AMONG 15 TO 49-YEAR-OLD FEMALES WITH AND WITHOUT DISABILITIES, IN ONTARIO, 2010/11–2019/20



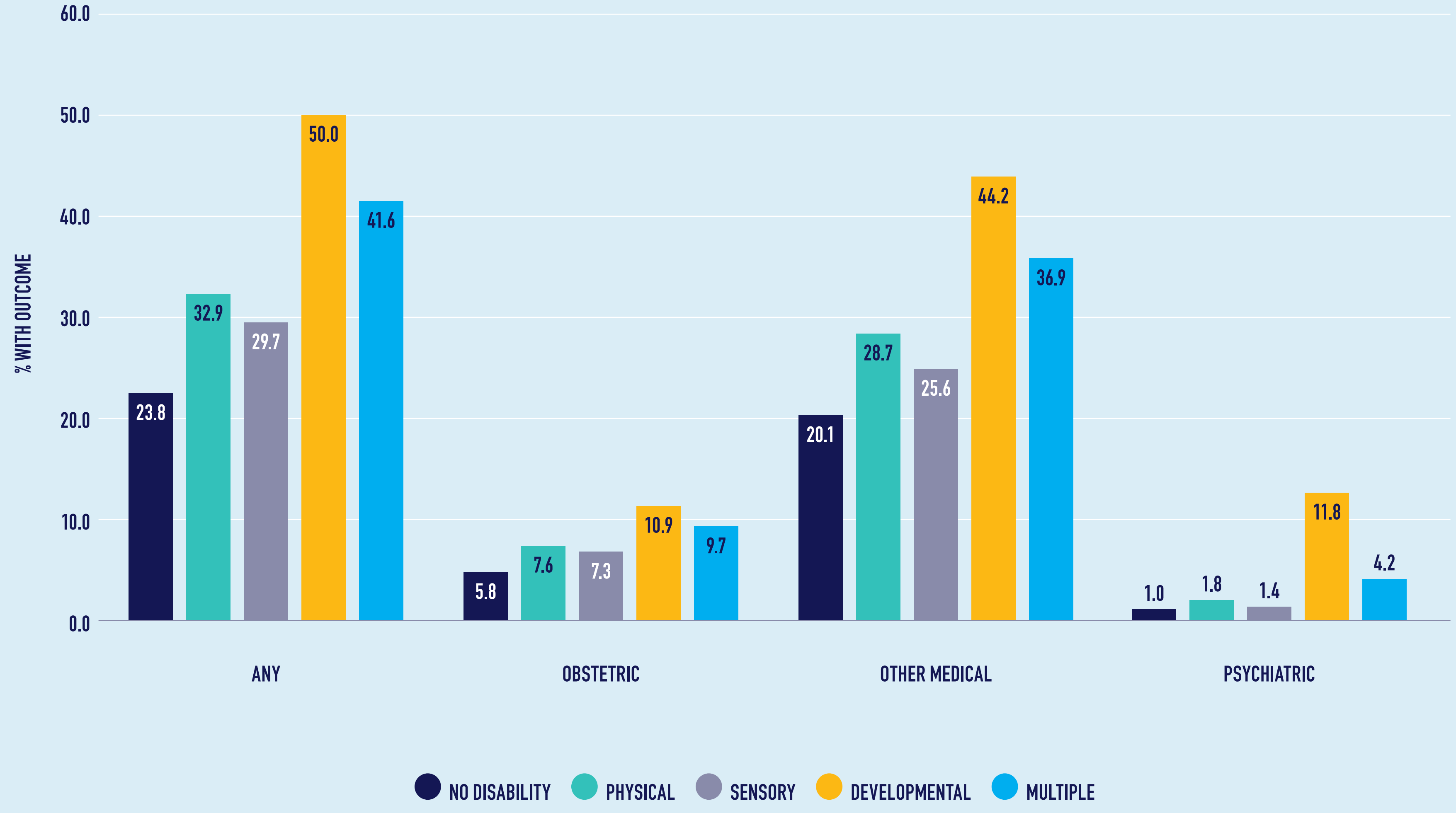
FINDINGS

- Most females with and without disabilities in Ontario received a routine six-week postpartum outpatient visit.

EXHIBITS AND FINDINGS

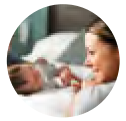
EXHIBIT 5.2

PREVALENCE OF POSTPARTUM EMERGENCY DEPARTMENT VISITS AMONG 15 TO 49-YEAR-OLD FEMALES WITH AND WITHOUT DISABILITIES, IN ONTARIO, 2010/11–2019/20



FINDINGS

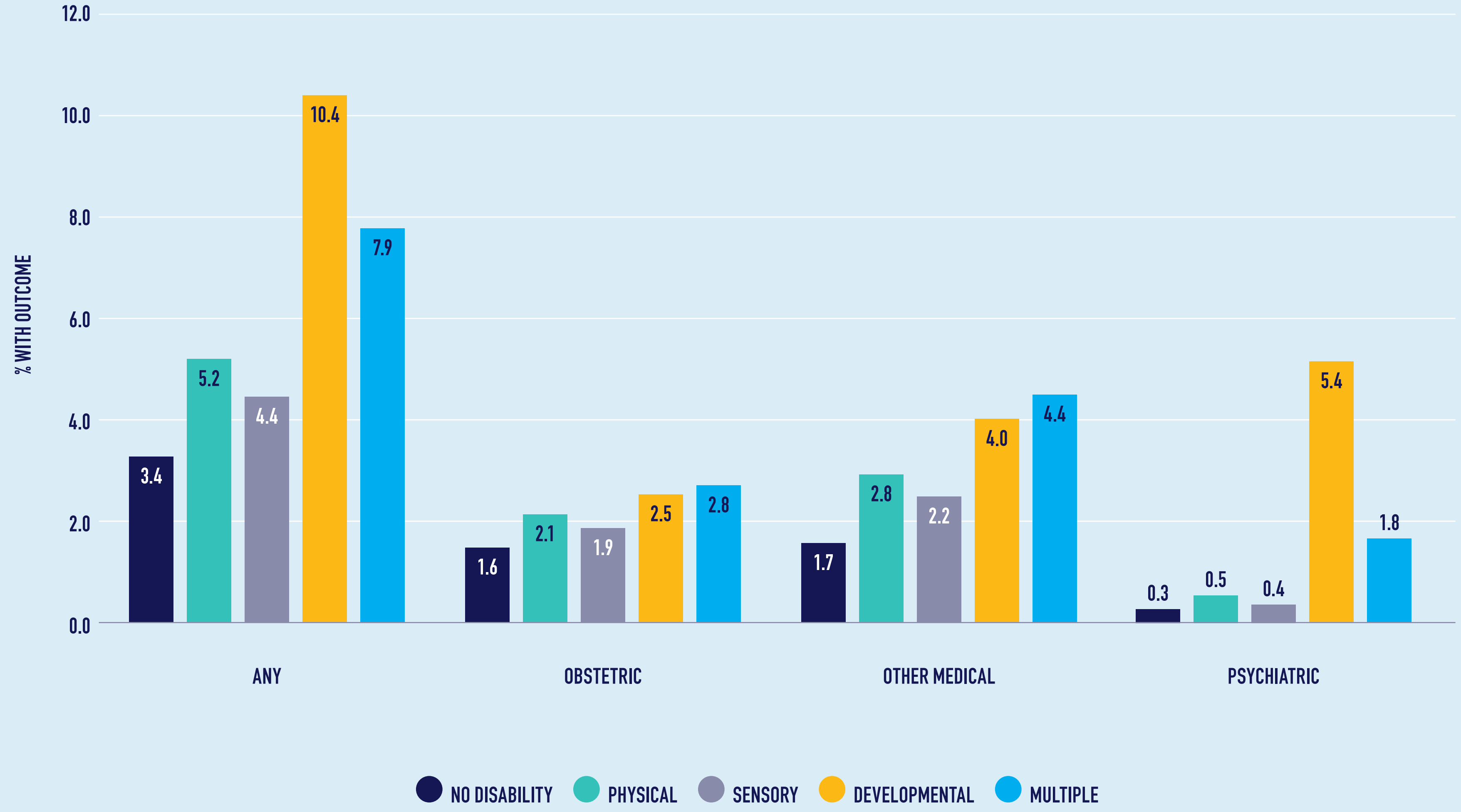
- Many females in Ontario had an emergency department visit in the postpartum period.
- Emergency department visits for obstetric reasons in the postpartum period were more common in females with developmental (10.9%) and multiple disabilities (9.7%) than in those without a disability (5.8%).
- Emergency department visits for other medical reasons in the postpartum period were more common in females with physical (28.7%), sensory (25.6%), developmental (44.2%) and multiple disabilities (36.9%) than in those without a disability (20.1%).
- Emergency department visits for psychiatric reasons in the postpartum period were more common in females with developmental (11.8%) and multiple disabilities (4.2%) than in those without a disability (1.0%).



EXHIBITS AND FINDINGS

EXHIBIT 5.3

PREVALENCE OF POSTPARTUM HOSPITAL ADMISSIONS AMONG 15 TO 49-YEAR-OLD FEMALES WITH AND WITHOUT DISABILITIES, IN ONTARIO, 2010/11–2019/20



FINDINGS

- Hospital admissions for other medical reasons in the postpartum period were more common in females with developmental (4.0%) and multiple disabilities (4.4%) than in those without a disability (1.7%).
- Hospital admissions for psychiatric reasons in the postpartum period were more common in females with developmental (5.4%) and multiple disabilities (1.8%) than in those without a disability (0.3%).

EXHIBITS AND FINDINGS

EXHIBIT 5.4

PREVALENCE OF SERIOUS PHYSICAL HEALTH COMPLICATIONS IN THE POSTPARTUM PERIOD AMONG 15 TO 49-YEAR-OLD FEMALES WITH AND WITHOUT DISABILITIES, IN ONTARIO, 2010/11–2019/20

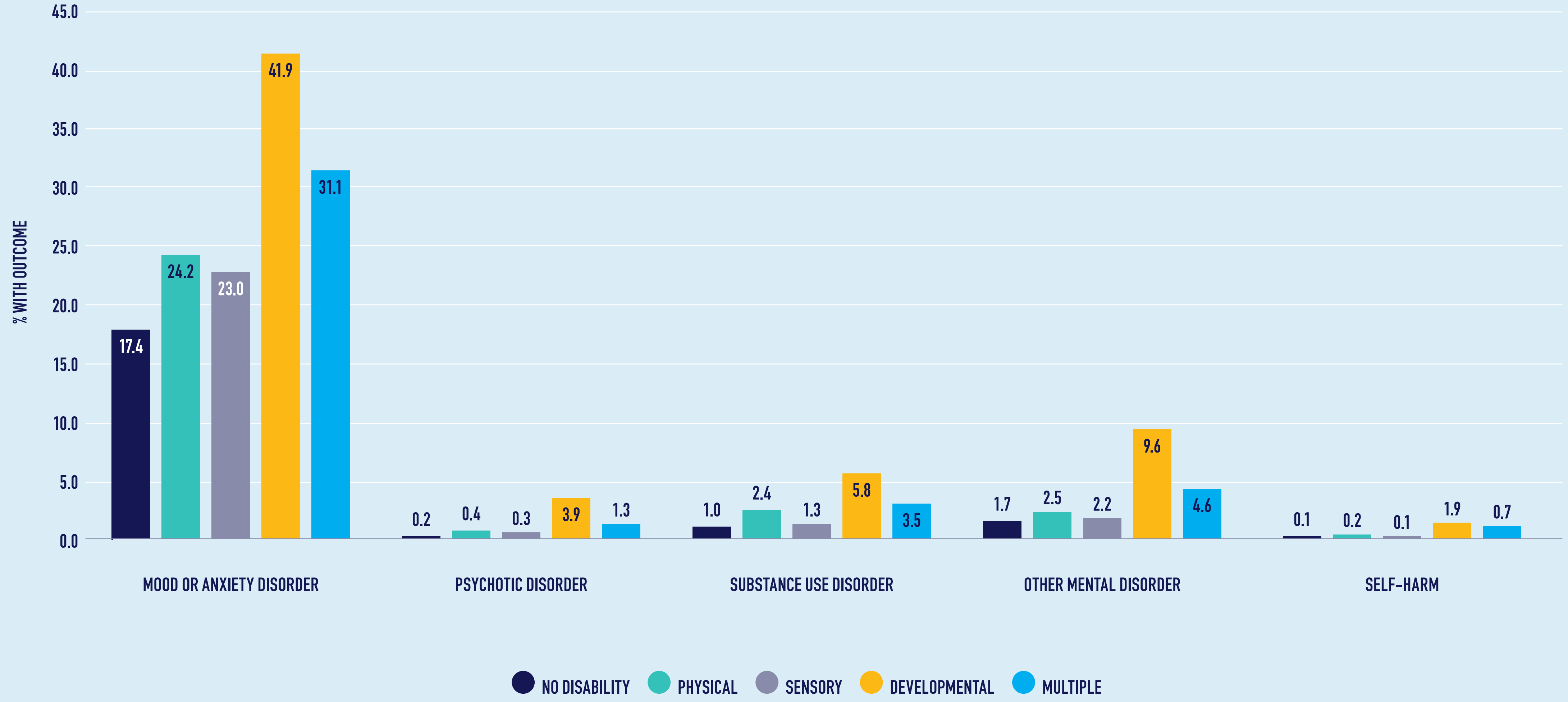
FINDINGS

- Serious physical health complications in the postpartum period were rare in females in Ontario overall.
- Females with developmental disabilities (1.1%) were more likely than those without a disability (0.3%) to have a serious physical health complication at 43-365 days postpartum.

EXHIBITS AND FINDINGS

EXHIBIT 5.5

PREVALENCE OF MENTAL HEALTH CONDITIONS IN THE POSTPARTUM PERIOD AMONG 15 TO 49-YEAR-OLD FEMALES WITH AND WITHOUT DISABILITIES, IN ONTARIO, 2010/11–2019/20



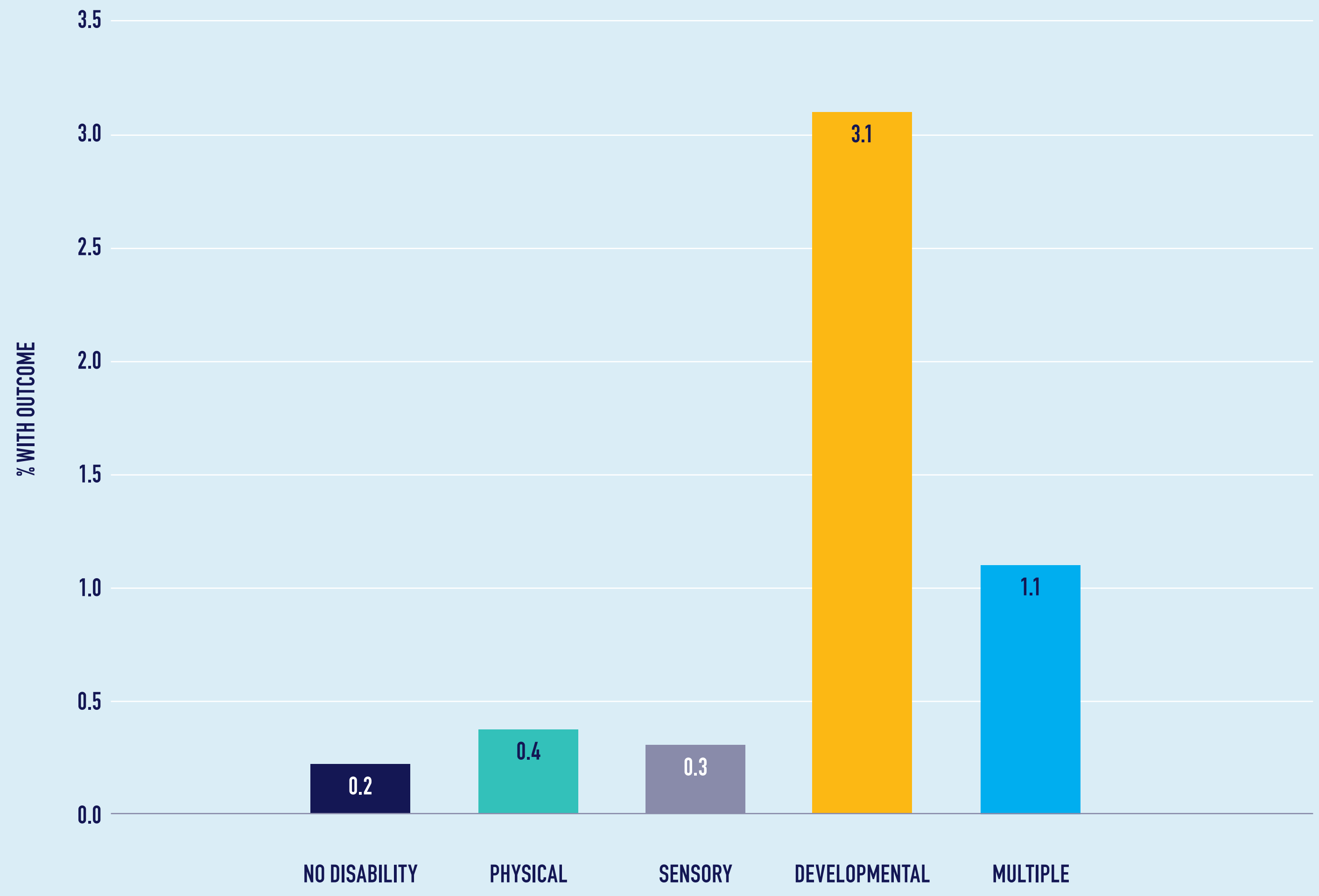
FINDINGS

- Mood and anxiety disorders in the postpartum period were more common in females with physical (24.2%), sensory (23.0%), developmental (41.9%) and multiple disabilities (31.1%) than in those without a disability (17.4%).
- Psychotic disorders in the postpartum period were more common in females with developmental (3.9%) and multiple disabilities (1.3%) than in those without a disability (0.2%).
- Substance use disorders in the postpartum period were more common in females with physical (2.4%), developmental (5.8%) and multiple disabilities (3.5%) than in those without a disability (1.0%).
- Other mental disorders in the postpartum period were more common in females with developmental (9.6%) and multiple disabilities (4.6%) than in those without a disability (1.7%).
- Self-harm in the postpartum period was more common in females with developmental (1.9%) and multiple disabilities (0.7%) than in those without a disability (0.1%).

EXHIBITS AND FINDINGS

EXHIBIT 5.6

PREVALENCE OF INTERPERSONAL VIOLENCE IN THE POSTPARTUM PERIOD AMONG 15 TO 49-YEAR-OLD FEMALES WITH AND WITHOUT DISABILITIES, IN ONTARIO, 2010/11—2019/20



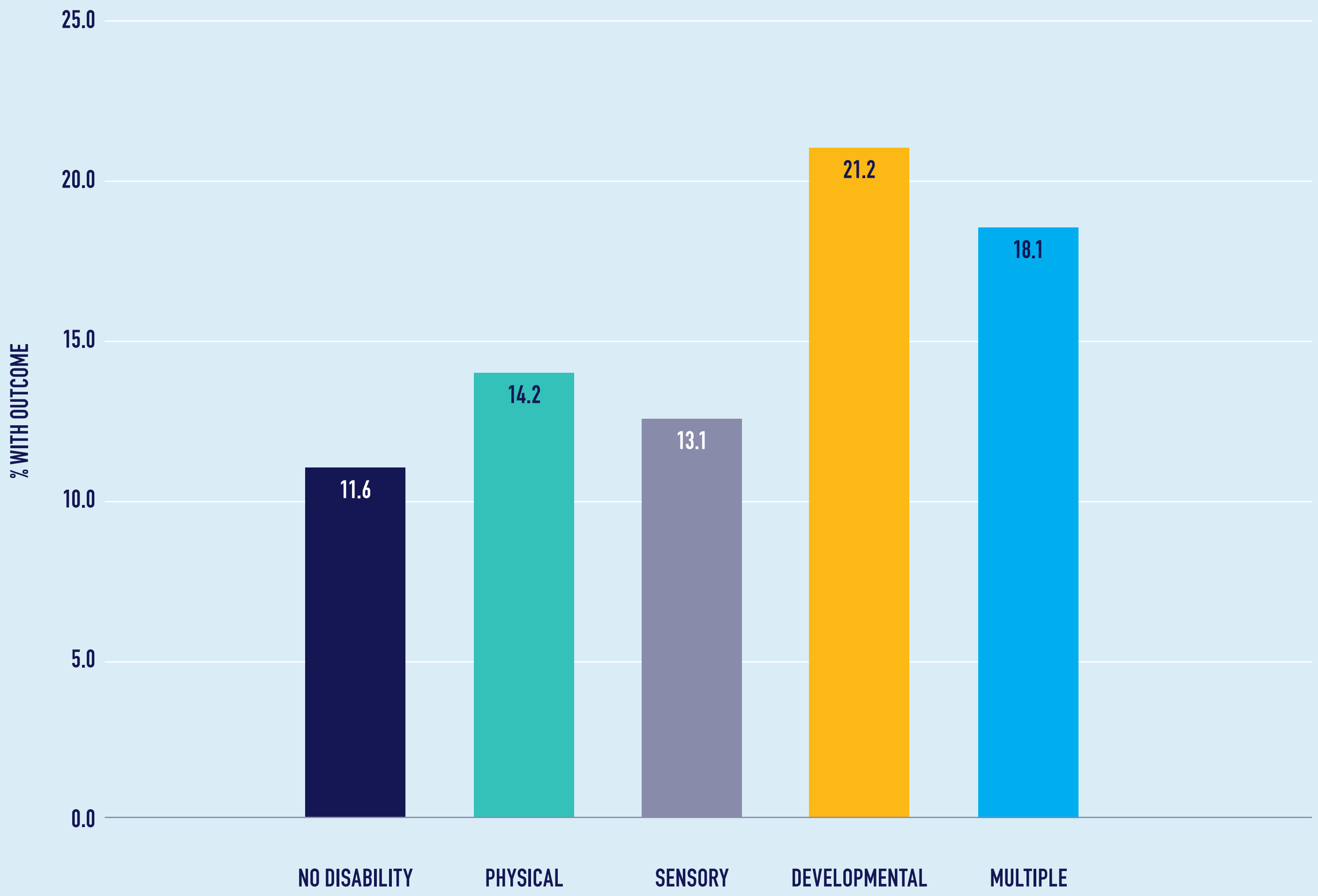
FINDINGS

- Emergency department visits for interpersonal violence in the postpartum period were rare in females in Ontario overall.
- Females with developmental (3.1%) and multiple disabilities (1.1%) were more likely than those without disabilities (0.2%) to have an emergency department visit for interpersonal violence in the postpartum period.

EXHIBITS AND FINDINGS

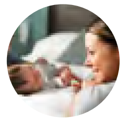
EXHIBIT 5.7

PREVALENCE OF NEONATAL INTENSIVE CARE UNIT ADMISSIONS AMONG NEWBORNS OF 15 TO 49-YEAR-OLD FEMALES WITH AND WITHOUT DISABILITIES, IN ONTARIO, 2010/11–2019/20



FINDINGS

- Newborns of females with developmental (21.2%) and multiple disabilities (18.1%) were more likely than those of females without a disability (11.6%) to have a neonatal intensive care unit admission in the first 28 days of life.



DISCUSSION

ACCESS TO OUTPATIENT POSTPARTUM CARE

Most females in Ontario receive the standard six-week postpartum outpatient visit.[1] These findings are similar to studies from the US[8] and the UK[9] showing that there are largely no differences in receipt of standard postpartum outpatient care in people with and without disabilities.

The lack of a difference in postpartum outpatient care use in people with versus without disabilities may reflect similar levels of access. However, this indicator does not reflect the quality of care.

EMERGENCY DEPARTMENT VISITS AND HOSPITAL ADMISSIONS IN THE POSTPARTUM PERIOD

Emergency department visits are common in the postpartum period in Ontario. However, females with disabilities have higher rates of emergency department visits compared to those without disabilities. Hospital admissions in the postpartum period are also more common in females with versus without disabilities, and particularly those with developmental and multiple disabilities. These findings are consistent with studies in the US showing higher rates of hospital care in people with disabilities in the postpartum period.[10-13]

These disparities may reflect gaps in the quality of outpatient care for people with disabilities in the postpartum period,[3,4] which might occur despite receipt of similar numbers of outpatient visits. Hospital admissions may further reflect greater serious obstetric, other medical and psychiatric needs in the postpartum period, which may be a result of pre-existing chronic conditions or new health complications arising postnatally.[4]

PHYSICAL HEALTH, MENTAL HEALTH AND OTHER NEEDS IN THE POSTPARTUM PERIOD

Serious physical health complications are rare in Ontario, but females with developmental disabilities have higher rates of these complications in the postpartum period than those without disabilities. There have been few studies examining serious physical health complications in the postpartum period in people with disabilities, with existing studies restricted to the birth hospital stay.[14-16] Our findings are consistent with these studies and show that risks of these outcomes extend across the late postpartum period. These elevated risks are likely due to a combination of social determinants of health, such as poverty, and pre-pregnancy health conditions, such as diabetes mellitus.

Females with disabilities in Ontario also have higher rates of mental health conditions in the postpartum period, consistent with a handful of studies on this topic from the US.[17,18] A number of factors likely contribute, including a history of mental illness, poverty, low social support and lack of access to services.[26,27]

Finally, while rare, females with disabilities in Ontario have elevated rates of interpersonal violence resulting in an emergency department visit in the postpartum period. There have been no quantitative studies on this topic. As with violence in pregnancy,[19,20] the reasons for elevated risk of interpersonal violence in people with disabilities in the postpartum period likely include lack of accessible violence-related services, social stereotypes that reduce personal agency, and economic and disability-related needs that increase reliance on others for support.[28]

DISCUSSION

NEWBORN HEALTH CARE NEEDS

Finally, we found elevated risk of neonatal intensive care unit admission among newborns of females with developmental and multiple disabilities in Ontario compared to those without disabilities. This finding is consistent with prior studies, including our recent meta-analysis of newborns of people with developmental disabilities.[24-26]

Possible reasons for this elevated risk include a combination of social determinants of health that impact the social support and resources of new parents with disabilities, as well as underlying maternal chronic illness, which may lead to increased risk of preterm birth[28] and thus greater newborn health needs.

IMPLICATIONS FOR POLICY AND PRACTICE

Educate service-providers on the provision of disability-affirming postpartum care

It is critical that all service-providers delivering postpartum and newborn health care receive training and education on disability and the delivery of respectful and disability-affirming care. This was identified as a critical issue in our in-depth qualitative interviews. For example, a nurse highlighted that health care providers should discuss newborn care strategies using a strengths-based approach rather than making ableist assumptions:

"I think people have opinions about who should be taking babies home, who shouldn't be taking babies home, you know? Somebody who is a quadriplegic who has a baby, you know, there is that bias from some nurses. I think it's crazy, about, 'They can't be left alone with the baby at home, how are they going to manage?' and that type of thing. So, there is sort of that stigma that goes with it, as opposed to saying, you know, 'What strategies have you got at home?' And, you know, having those kinds of conversations."

Provide enhanced outpatient care throughout the extended postpartum period

Higher rates of hospital care in people with disabilities across the extended postpartum period suggest gaps in their outpatient care. While there were no disparities in receipt of routine outpatient postpartum care in people with disabilities, our data suggest the need for greater intensity of postpartum care, for example, with multiple visits across the extended postpartum period. Studies have shown such extended postpartum care is effective and can use alternative modalities, such as telephone calls and nurse home visits.[29] Megan, who has caudal regression syndrome, described how she needed more care than just a single six-week postpartum visit:

"There's that gap once your baby's born, they move on to the next pregnant mom. And the flaw in the system, I think, is for those six weeks, before you have your six-week check-in cleared, why aren't you still just going to labour and delivery to see the team that needs to see you?"

DISCUSSION

Provide integrated postpartum mental health supports

Our findings also show a particular need for mental health supports for people with disabilities in the postpartum period to improve prevention, early detection and treatment of postpartum mental illness. Physical and mental health care could be provided in tandem using integrated and collaborative care approaches.[30] Luciana, who has multiple physical disabilities, identified postpartum mental health care as an important priority and commented on the risks she perceived in having postpartum depression and access to strong pain medications at home:

> *"I think that was brushed off and it's so dangerous. If you have a mom with a high risk of postpartum depression, who has heavy, hardcore painkillers at home, I think that's a deadly combination… I was almost suicidal… I was disappointed… I definitely wish that there was some sort of mental health support. And something that you can probably get started towards the end of the pregnancy and continue on, not just do it until the baby comes and see if you're going to develop postpartum depression."*

Mental health supports for people with disabilities in the postpartum period should also consider their broader social needs which may contribute to and exacerbate postpartum mental health challenges. For example, one of the public health nurses we interviewed explained how mental health and social needs are closely linked:

> *"I think it's just a lot of the issues are accessing things, right? Like accessing programs out there, even funding for things. A lot of moms are on social assistance, it's barely enough to cover what they need and then if you have a disability you're at higher risk of having all of these other issues. The mental health piece and issues in home … And we do see that those struggles are there and unfortunately there aren't enough services out there to provide the support that parents need, when they have a disability."*

Provide enhanced newborn care supports

Our data also show the importance of addressing the newborn health care needs of people with disabilities. This includes providing enhanced supports to prevent complications, as well as ensuring newborn care spaces, including neonatal intensive care units, are accessible to parents with disabilities. For example, one participant, Siobhan, who is blind, commented how difficult it was to navigate the neonatal intensive care unit:

> *"It's set up to help the babies, but it's just assumed that the parents are fully abled, right? They have these little chairs and small spaces that I don't know how you would get around if you needed a walker or something like that. I was often nervous to touch my daughter because I knew she had a lot of tubes and sensors on her and I didn't know where they were and what they were for. Ten minutes up front explaining all this would have helped me a lot. If someone had just said, 'Okay, so here's your daughter and she has a breathing tube here and a feeding tube here that are up her nose, that's really important that those don't get moved'. No one tells you what it means."*

DISCUSSION

DATA NEEDS

Our findings should be interpreted in the context of several important limitations:

- As in Chapter 3, we were able to measure the quantity of outpatient postpartum care received, but we were unable to measure its quality. We explore this in more detail in Chapter 6.
- Also similar to Chapter 3, we were unable to measure symptoms of postpartum mental illness. We were only able to capture mental health conditions resulting in a health care encounter with a physician. If disabled people are less likely than those without disabilities to access care for their symptoms, or are more likely to see other mental health professionals (e.g., social workers), their mental illness rates may be underestimated.
- Finally, we were unable to measure experiences of interpersonal violence that did not result in an emergency department visit. People with disabilities experience barriers to seeking care related to interpersonal violence.[28] The rates of interpersonal violence that we observed are therefore likely underestimated. We also had no information on the perpetrator of interpersonal violence, but other research shows that most violence experienced around the time of pregnancy is by an intimate partner.[32]

FUTURE RESEARCH

There are several areas where more research could help to inform policy and clinical practice related to postpartum care for people with disabilities, including:

- Studies on postpartum outpatient care access and postpartum health disparities in people with disabilities facing other forms of oppression, such as Black and Indigenous people with disabilities, and sexual and gender minority people with disabilities;
- Studies on structural and social factors that contribute to higher rates of hospital care, serious physical health complications and mental health conditions in people with disabilities in the postpartum period, and particularly those with developmental and multiple disabilities;
- Studies on the effectiveness of extended postpartum care for people with disabilities, including care using alternative modalities such as telephone-based and nurse home visits; and
- Studies on the utility of interventions outside of the health care system (e.g., peer support) for people with disabilities in the postpartum period.

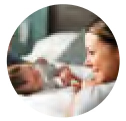
The results of this additional research could be used to help identify new areas where we need to improve the postpartum care of people with disabilities, and how to better meet their needs.

Conclusion

This chapter shows that most females in Ontario receive a standard six-week postpartum outpatient care visit, regardless of disability status. Females with disabilities are more likely than those without disabilities to have emergency department visits and hospital admissions in the postpartum period. They are also more likely to experience rare but serious physical health complications, as well as mental health conditions and interpersonal violence in the postpartum period. Newborns of females with developmental and multiple disabilities are more likely than newborns of females without disabilities to experience neonatal intensive care unit admission. These findings show the importance of coordinated, multidisciplinary care across the extended postpartum period that is responsive to the needs of people with disabilities and their newborns.

Related publications

- Brown HK, Chen S, Guttmann A, Havercamp S, Parish S, Ray JG, et al. Neonatal outcomes of mothers with a disability. *Pediatrics* 2022; 150(3):e2021055318.
- Brown HK, Chen S, Vigod SN, Guttmann A, Havercamp S, Parish S, et al. A population-based analysis of postpartum acute care use among women with disabilities. *AJOG-MFM* 2022; 4(3):100607.
- Brown HK, Ray JG, Chen S, Guttmann A, Havercamp S, Parish S, et al. Association of pre-existing disability and severe maternal morbidity or mortality in Ontario, Canada. *JAMA Netw Open* 2021; 4(1):e2034993.
- Brown HK, Saunders N, Chen S, Leslie K, Vigod SN, Fung K, et al. Disability and interpersonal violence in the perinatal period. *Obstet Gynecol* 2022; 140(5):797–805.
- Brown HK, Vigod SN, Chen S, Guttmann A, Havercamp S, Parish S, et al. Perinatal mental illness among women with disabilities: a population-based cohort study. *Soc Psych Psychiatr Epidemiol* 2022; 57(11):2217–28.



RETURN TO PREVIOUS PAGE

References

1. Provincial Council for Maternal and Child Health. *Standards of postnatal care for mothers and newborns: survey report.* Toronto: PCMCH; 2017.
2. Brousseau EC, Danilack V, Cai F, Matteson KA. Emergency department visits for postpartum complications. *J Womens Health* 2018; 27:253–7.
3. Clapp MA, Little SE, Zheng J, Kaimal AJ, Robinson JN. Do hospital postpartum readmission rates reflect obstetrical care quality? *Am J Obstet Gynecol* 2017; 216:S411.
4. Sperlich M, Seng JS, Li Y, Taylor J, Bradbury-Jones C. Integrating trauma-informed care into maternity care practice: conceptual and practical issues. *J Midwifery Womens Health* 2017; 62(6):661–72.
5. Public Health Agency of Canada. *Family-Centred Maternity and Newborn Care: National Guidelines.* Ottawa: PHAC; 2017.
6. Berndl A, Ladhani N, Wilson RD, Basso M, Jung E, Tarasoff LA, et al. Guideline No. 416: labour, delivery, and postpartum care for people with physical disabilities. *J Obstet Gynaecol Can* 2021; 43(6):769–80.
7. Sullivan WF, Diepstra H, Heng J, Ally S, Bradley E, Casson I, et al. Primary care of adults with intellectual and developmental disabilities: 2018 Canadian consensus guidelines. *Can Fam Physician* 2018; 64(4):254–79.
8. Clements KM, Mitra M, Zhang J, Parish SL. Postpartum health care among women with intellectual and developmental disabilities. *Am J Prev Med* 2020; 59(3):437–44.
9. Redshaw M, Malouf R, Gao H, Gray R. Women with disability: the experience of maternity care during pregnancy, labour and birth and the postnatal period. *BMC Pregnancy Childbirth* 2013; 13:174.
10. Gavin NI, Benedict MB, Adams EK. Health service use and outcomes among disabled Medicaid pregnant women. *Womens Health Issues* 2006;16(6):313–22.
11. Mitra M, Parish SL, Akobirshoev I, Rosenthal E, Simas TAM. Postpartum hospital utilization among Massachusetts women with intellectual and developmental disabilities: a retrospective cohort study. *Mat Child Health J* 2018;22(10):1492–1501.
12. Mueller BA, Crane D, Doody DR, Stuart SN, Schiff MA. Pregnancy course, infant outcomes, rehospitalization, and mortality among women with intellectual disability. *Disabil Health J* 2019;12(3):452–9.
13. Schiff MA, Doody DR, Crane DA, Mueller BA. Pregnancy outcomes among deaf women in Washington State, 1987–2012. *Obstet Gynecol* 2017; 130:953–60.
14. Gleason JL, Grewal J, Chen Z, Cernich AN, Grantz KL. Risk of adverse maternal outcomes in pregnant women with disabilities. *JAMA Netw Open* 2021;4(12):2138414.
15. Horner-Johnson W, Garb B, Darney BG, Biel FM, Caughey AB. Severe maternal morbidity and other perinatal complications among women with physical, sensory, or intellectual and developmental disabilities. *Paediatr Perinat Epidemiol* 2022; 36(5):759–68.
16. Mitra M, Akobirshoev I, Valentine A, Brown HK, Moore Simas TA. Severe maternal morbidity and maternal mortality in women with intellectual and developmental disabilities. *Am J Prev Med* 2021; 61(6):872–81.
17. Mitra M, Iezzoni LI, Zhang J, Long-Bellil LM, Smeltzer SC, Barton BA. Prevalence and risk factors for postpartum depression symptoms among women with disabilities. *Mat Child Health J* 2015; 19(2):362–72.
18. Alhusen JL, Hughes RB, Lyons G, Laughon K. Depressive symptoms during the perinatal period by disability status: findings from the United States Pregnancy Risk Assessment Monitoring System. *J Adv Nurs* 2022; 79(1):223–33.
19. Mitra M, Manning SE, Lu E. Physical abuse around the time of pregnancy among women with disabilities. *Maternal Child Health J* 2012; 16:802–6.
20. Mwachofi AK. Violence against pregnant women with disabilities. *J Health Disparities Res Pract* 2016; 9(2):28–45.
21. Ray JG, Park AL, Dzakpasu S, Dayan N, Deb-Rinker P, Luo W, et al. Prevalence of severe maternal morbidity and factors associated with maternal mortality in Ontario, Canada. *JAMA Netw Open* 2018; 1(7):e184571.
22. Saunders N, Plumptre L, Diong C, Gandhi S, Schull M, Guttmann A, et al. Acute care visits for assault and maltreatment before vs during the COVID-19 pandemic in Ontario, Canada. *JAMA Health Forum* 2021; 2:e211983.
23. Tarasoff L, Murtaza F, Salaeva D, Carty A, Hamilton A, Brown HK. Health of newborns and infants born to women with disabilities: a systematic review and meta-analysis. *Pediatrics* 2020; 146(6):e20201635.
24. Mitra M, Clements KM, Zhang J, Iezzoni LI, Smeltzer SC, Long-Bellil LM. Maternal characteristics, pregnancy complications, and adverse birth outcomes among women with disabilities. *Med Care* 2015; 53(12):1027–32.
25. Schiff MA, Doody DR, Crane DA, Mueller BA. Pregnancy outcomes among visually impaired women in Washington State, 1987-2014. *Disabil Health J* 2021; 14(3):101057.
26. Robertson E, Grace S, Wallington T, Stewart DE. Antenatal risk factors for postpartum depression: a synthesis of recent literature. *Gen Hosp Psych* 2004; 26(4):289–95.
27. Havercamp SM, Scott HM. National health surveillance of adults with disabilities, adults with intellectual and developmental disabilities, and adults with no disabilities. *Disabil Health J* 2015; 8(2):165–72.
28. Hughes K, Bellis MA, Jones L, Wood S, Bates G, Eckley L, et al. Prevalence and risk of violence against adults with disabilities: a systematic review and meta-analysis of observational studies. *Lancet* 2012; 379:1621–9.
29. Thomson K, Moffat M, Arisa O, Jesurasa A, Richmond C, Odeniyi A, et al. Socioeconomic inequalities and adverse pregnancy outcomes in the UK and Republic of Ireland: a systematic review and meta-analysis. *BMJ Open* 2021; 11(3):e042753.
30. Lavender T, Richens Y, Milan SJ, Smyth RM, Dowswell T. Telephone support for women during pregnancy and the first six weeks postpartum. *Cochrane Database Syst Rev* 2013; 7:CD009338.
31. Katon WJ, Lin EH, Von Korff M, Ciechanowski P, Ludman EJ, Young B, et al. Collaborative care for patients with depression and chronic illnesses. *N Engl J Med* 2010; 363(27):2611–20.
32. National Center for Injury Prevention and Control. *National Intimate Partner and Sexual Violence Survey: 2015 data brief – updated release.* Atlanta: Centers for Disease Control and Prevention; 2018.

MIRIAM lives in a large city with her son. Miriam was diagnosed with multiple sclerosis in her early 30s.

Trauma from her multiple sclerosis diagnosis and questions about how pregnancy would affect her condition significantly impacted her pregnancy and breastfeeding experience and her interactions with service-providers.

Miriam's baby was breeched, and after several attempts to turn the baby, her obstetrician felt she should have a Caesarean section. Miriam had concerns about receiving an epidural because of a previous traumatic experience with a spinal tap when she was diagnosed with multiple sclerosis: *"I was more worried about the epidural than the c-section. I spoke to my neurologist. She said that it would be fine and not to worry. That helped a lot. But I had to go to my specialist [to get this reassurance]. Everybody else was like, 'I don't really know what to say to that concern.'"*

Despite receiving reassurance from her neurologist, Miriam felt the Caesarean section birth plan that she had created was ignored by her obstetrician, and her anaesthesiologist offered an unhelpful opinion about the epidural immediately before her Caesarean delivery: *"'Oh, you have MS? This is a big procedure, and you should know you will be vulnerable to an attack after this'. I had been given zero choice. That was the mood and atmosphere in which my child was delivered. My neurologist later called him an asshole, said that he had no business talking to me about a neurological condition and giving a prognosis."*

Miriam was told to breastfeed for at least three months to try to avoid a multiple sclerosis flare-up. However, after experiencing breastfeeding difficulties, she had trouble accessing a lactation consultant: *"It just seems to be such a huge oversight to me, that one medical practitioner can say, 'This is part of your treatment plan. You really, you know, focus on breastfeeding for at least the first three months to try and prevent an attack' and that doesn't register anywhere! So, what's the point of saying that? You put all the onus on the individual and there's no help."*

When asked about her advice for health care providers to improve pregnancy care for people with disabilities, Miriam said: *"Listen to the people about what their particular needs are… I think that there may have been supports available to me and I didn't know about them because the pamphlets were just so quick, but it would have been really nice if I had somebody that I could access to come home and help me with stuff."*

Based on an interview with a study participant. The name and details have been changed for privacy.

06

Pregnancy Care Experiences: Unifying Themes

MAIN MESSAGES

- **Provision of high-quality pregnancy care to people with disabilities requires an understanding of their experiences of pregnancy care, and those of service-providers and decision-makers.**
- **We described challenges in and facilitators of high-quality pregnancy care identified by people with disabilities, service-providers and decision-makers in Ontario.**
- **People with disabilities identified several challenges, including accessibility barriers, fragmented care across services, poor service-provider knowledge, lack of respect from service-providers, ableist service-provider assumptions, and inadequate information and decision-making autonomy.**
- **Facilitators identified by people with disabilities included advocacy, flexible care strategies and adapted and hands-on help.**
- **Service-providers and decision-makers also identified many challenges in pregnancy care for people with disabilities, including inflexible fee-for-service remuneration policies, inadequate education and training and limited resources.**
- **Facilitators identified by service-providers and decision-makers included policy changes to improve access, service-provider advocacy for their patients, holistic care and tailored care.**
- **Together, these findings show that more needs to be done to improve the quality of pregnancy care for people with disabilities in Ontario.**

Introduction

High-quality pregnancy care is defined by the provision of timely, accessible, respectful, family-centred and evidence-based care across the pregnancy period, from preconception to postpartum and newborn care.[1-3] The pregnancy health outcomes examined in the previous chapters of this Report reflect important health disparities experienced by people with disabilities and their newborns that must be addressed through better pregnancy care. However, these data do not specifically address individuals' experiences of accessing pregnancy care. To create high-quality pregnancy care policies and clinical practices that are responsive to the needs of all families, these lived experiences must be explored in parallel with the observed population-level health disparities.

To inform the development of high-quality pregnancy care for people with disabilities, the main questions this chapter will answer are:

- What are the challenges and facilitators of high-quality pregnancy care identified by people with disabilities?
- What are the challenges and facilitators of high-quality pregnancy care for people with disabilities identified by service-providers and decision-makers?

BACKGROUND

A number of qualitative studies, mostly from the US, have examined pregnancy care experiences in people with disabilities.[4-20] In these studies, people with disabilities identified numerous challenges to pregnancy care, including physically inaccessible health care settings, communication barriers such as limited interpretation services and use of confusing medical jargon, lack of health care provider knowledge, stigmatizing health care provider attitudes toward disability and pregnancy, and a lack of tailored resources. Likewise, service-providers identified challenges to providing pregnancy care to people with disabilities, including lack of training related to disability.[21-23] While these studies are informative, there are few Canadian studies on this topic.

In this chapter, we report the challenges to and facilitators of pregnancy care for people with disabilities identified by 31 people with disabilities and 31 service-providers and decision-makers in Ontario, who were interviewed in 2019–2020. These data are critical for contextualizing the population-level health outcomes data in the prior chapters and informing the overall recommendations presented in Chapter 7. For details on how the themes were identified in this chapter, refer to the Technical Appendix.

FINDINGS

EXPERIENCES OF PEOPLE WITH DISABILITIES

Challenges in high-quality pregnancy care

Common challenges in pregnancy care identified by the people with disabilities we interviewed included:

1. Accessibility barriers;
2. Fragmented care across services;
3. Poor service-provider knowledge;
4. Lack of respect from service-providers;
5. Ableist service-provider assumptions; and
6. Inadequate information and decision-making autonomy.

Accessibility barriers

Most people with disabilities in our interviews reported accessibility barriers related to both the physical environment and communication. Many participants with physical disabilities described how health care spaces were not set up with the needs of people who use mobility devices in mind. For example, Megan, who uses a wheelchair, shared how her husband was necessary for every prenatal care appointment to help with lifting and transferring:

"My husband's friend took me to an appointment, but she wouldn't have been able to lift me, so I do remember I had to pee and it was very difficult at that point to transfer but I hadn't really thought through if there was anyone to help me and I didn't ask and I just managed but I was like, 'This was not wise'… but yeah, my husband was necessary for every appointment."

Participants with sensory and developmental disabilities in particular also reported significant communication barriers. For example, Robyn described how lack of access to an American Sign Language interpreter during her delivery exacerbated the trauma for her and her husband when they learned one of their twins was stillborn.

Instead of receiving the news together, Robyn's husband, who is hearing, received the information first and was forced to convey it to Robyn without guidance or support:

"And I could see my husband was crying and there was no interpreter around. And the nurse came back and she said something to my husband and he was listening and my husband was just in total shock. And he signed 'dead.' And it didn't hit me right away because I had the other one with me. I was happy, I was looking at the other one that was in my arms. But then he signed 'dead.'"

FINDINGS

EXPERIENCES OF PEOPLE WITH DISABILITIES

Participants who were blind similarly shared how lack of accessible resources made it difficult for them to obtain information about pregnancy and postpartum care. Siobhan shared:

> ***“When they give information to parents, they give you a bunch of pamphlets, right? ‘Here’s a bunch of mysterious papers,’ you know? And usually I just have to recycle it because I don’t know what this is, so I do really appreciate anytime someone can email me that as a PDF or anything. Or even just tell me the key information, so it is helpful… So just making that information a bit more accessible is helpful.”***

Health care providers’ use of medical jargon, without further explanation, was especially problematic for participants with developmental disabilities.

For example, Leah, who has a developmental disability, shared:

> ***“[Service-providers] explain, but they should sit down and actually explain a little better.”***

Fragmented care across services

Participants also reported a lack of coordinated care across the various services they received during pregnancy and postpartum. For people with physical disabilities in particular who often had multiple health care providers during pregnancy (e.g., fertility specialists,obstetricians, disability and other medical specialists), many felt they had to organize their own care. Luciana, who has multiple disabilities including rheumatoid arthritis, described how she had to “put pieces together” herself:

> ***“I was the one who told [service-provider], ‘Oh, make sure to get the high-risk clinic and the other hospital. Did you hear about this person who has the experience with pregnancy and rheumatoid arthritis?’”***

FINDINGS

EXPERIENCES OF PEOPLE WITH DISABILITIES

Poor service-provider knowledge

Most people with disabilities felt the service-providers involved in their pregnancy care lacked knowledge about disability. This lack of knowledge often resulted in service-providers making assumptions and generalizations about people with disabilities. For example, Tanya, who has Marfan syndrome and Ehlers-Danlos syndrome and uses a wheelchair, described a situation where her health care provider did not recognize that Marfan syndrome manifests differently in different people, and did not appear open to learning from Tanya. Tanya remembered the health care provider saying: *"I have no idea why you use a wheelchair. I see people with Marfan syndrome all the time and none of them use wheelchairs."*

This lack of knowledge also meant that service-providers often did not recognize the different or unique accessibility needs of their patients, or their responsibility as providers to address those accessibility needs. Shannon, who is Deaf, recounted how her health care provider did not realize that although she can read lips and speak, she still needed an American Sign Language interpreter during prenatal care appointments:

"When it's something medical, I'm like, 'Well, I don't understand you. I need an interpreter.' And they don't understand why I need an interpreter because I can speak so well. Just because I can speak well doesn't mean I can understand what you're saying."

Sometimes, this lack of service-provider knowledge meant that people with disabilities found themselves having to educate their service-providers about their disability. Zahra, who is blind, had this experience when engaging with public health nurses in the postpartum period:

"They are helpful, but the problem was they used to learn from me because it was their first time to take care of [someone who is] visually impaired. Even myself, I was wondering what happened, like they don't know anything about the visually impaired and how do they work? How they do these things, you know?"

Ultimately, service-providers' lack of knowledge made participants, especially those with developmental disabilities, reluctant to disclose their disability. Danielle, who has a developmental disability, shared:

"So, it's frustrating trying to explain how you experience things and doctors and other people don't understand… [so] I didn't even tell my own doctor. I don't know, he probably wouldn't understand it anyways, so I don't bother because people don't understand it. Even the child welfare [workers] don't… People think that they know what it is, but they don't."

FINDINGS

EXPERIENCES OF PEOPLE WITH DISABILITIES

Lack of respect from service-providers

Participants also described experiences of disrespect from service-providers. Corey, who is autistic, shared how they felt they were treated *"like a diagnosis,"* not a person:

> *"The ones who were a lot more just treating me like a regular person in the sense of like, you know, not assuming that I can't do something or – instead of treating me more like a child. Because that's something I find a lot in general with medical professionals is they can treat you that way, especially with autism. Just treat people as people and not as the diagnosis."*

In some instances, service-providers did not seem to be able to trust disabled people's knowledge about their own disability. Alyssa, who has cerebral palsy, described how her providers continually questioned how her disability impacted her ability to feel labour contractions:

> *"I had to keep explaining to the different nurses and medical staff every rotation what it was I had and why I was there at the hospital. A lot of people thought I was paralyzed or that I might not be able to feel contractions because I was paralyzed, and I said look, no, that's what I have. And some of them would even argue with me, like 'No, you're paralyzed…' 'No, I can still feel my legs…' And I think either because of my disability or not, they just seemed to not always be certain that they could take my word for things."*

People with disabilities also noted how they were treated differently when they had a non-disabled support person (e.g., partner, parent) with them at appointments. For example, Laura, who has multiple disabilities, described how having a support person with her resulted in a noticeable change in her health care provider's behaviour:

> *"They look at me and they're like, 'Yeah okay' and they push me to the side. And now because I have somebody else coming to that appointment with me, now I'm getting answers. Now they're like, 'Oh we should actually look at this because we have somebody higher up. She must actually know what she's talking about.'"*

EXPERIENCES OF PEOPLE WITH DISABILITIES

Ableist service-provider assumptions

People with disabilities felt that service-providers frequently assumed that they should not become pregnant, or made assumptions about their ability to have a healthy pregnancy. For example, Alyssa, who sometimes uses a wheelchair, shared:

> *"I met the doctor for the first time when I went in to confirm the pregnancy. And he was like 'What brings you here?'... 'Oh, I just found out that I'm pregnant.' And he looked down at my wheelchair for a second, and he looked at me, and he said, 'Are you here to get an abortion?' And I was absolutely stunned. It was like, 'No, we've been trying for a year and we're really excited,' and that was a really weird and terrible kind of experience."*

Service-providers also often questioned participants' ability to parent. Zahra, a recent immigrant to Canada, even considered returning to her home country after her obstetrician questioned her ability to care for her infant because she was blind:

> *"One day my obstetrician told my husband, 'You are not supposed to work or otherwise you have to find someone to take care of your baby because your wife cannot see and can't see the baby if she would turn blue... The baby might be taken away by the government.' ...I was feeling like I was about to cry, and I told my husband, 'I better go back home rather than surrender my child to the government.'"*

These ableist service-provider assumptions about pregnancy and parenting had a major impact on participants' willingness to seek health care. For example, Johanna, who experienced postpartum depression, felt she could not ask for help due to the feeling of needing to prove herself as a parent to her service-providers:

> *"As a disabled mom, I felt I had to make it seem like I was doing better than any 'normal' mom because I was afraid if people thought I couldn't do it, then they would assume that it was a mistake for me to have a kid or look back and say, 'Why did she do this?' or the judgments. Not just a child welfare call but 'why did she have a kid?' kind of thing. I didn't reach out to supports because I was trying to hide that it was really hard. Even if people told me 'Yes, it's really hard,' I felt I had to still prove that I was doing okay."*

Others declined supports like home visits in the postpartum period because of fears of how health care providers might treat them if they learned they had a disability. For example, Wendy, who has cerebral palsy, shared:

> *"I declined a public health nurse visit because of my disability and fear of lack of understanding from their part. I don't think I would've disclosed any problems to them, because I don't know who they are. They don't know who I am. I didn't utilize the nurse at all because of my fear of disclosure and judgement."*

Inadequate information and decision-making autonomy

Several people with disabilities also noted a lack of information about the possible impact of disability on pregnancy, and of pregnancy on disability-related symptoms and progression. This lack of information and resources impacted their autonomy and their ability to participate fully in decisions about their care. They also felt there was no space to ask their service-providers for this information. For example, Miriam, who has multiple sclerosis, shared:

> *"Yeah. So I—that was just, it was awful. It was awful not to be able to make the decisions that I felt I needed to make and wanted to make. And there were all these things that I wanted to ask people about and what the implications would be and there was no place even to have those conversations."*

FINDINGS

EXPERIENCES OF PEOPLE WITH DISABILITIES

Facilitators of high-quality pregnancy care

On the other hand, people with disabilities also identified several facilitators of high-quality pregnancy care, including:

1. **Advocacy;**
2. **Flexible care strategies; and**
3. **Adapted and hands-on help.**

Advocacy

Advocacy came in many forms, including advocacy from specific service-providers, advocacy from family and friends and self-advocacy. For example, a few participants identified health care providers who advocated for their disability-related needs, which contributed significantly to positive pregnancy care experiences. Mackenzie described a situation where her obstetrician's advocacy was critical for booking an American Sign Language interpreter at the hospital:

> *"The hospital said 'We won't get an interpreter, we won't pay'... The doctor heard and was actually quite shocked, so he went and said, 'You need to get an interpreter.' 'No, we're not, we shouldn't have to pay.' … The doctor said, 'You need it,' and it happened, and they reluctantly agreed to book me an interpreter."*

More often, however, participants relied on family members and friends for support to make up for a lack of disability-related accommodations in pregnancy care settings. For participants with physical disabilities, this sometimes meant family members having to help lift and transfer them. Johanna, who has limb girdle muscular dystrophy and osteoporosis, shared her experience at a pregnancy clinic:

> *"When you're on the table and they need to do a cervical thing or examine you down there, having something to hold your legs was a big issue. They just had regular stirrups and I can't, my legs won't sit in the stirrups that way. So often, my husband was left holding my leg up in appointments and trying not to go numb [chuckles] while he was trying to hold my leg. And anytime I had an ultrasound, that's what we had to do... If you just got those thigh-holder things, that would work perfectly for me, because you could just relax them and it's actually really comfy. But they just had regular stupid stirrups."*

Similarly, participants with sensory disabilities frequently reported having to rely on family members and friends to help with communication in care settings. For example, Siobhan, whose third child died due to a congenital heart defect, shared how her husband explained what was happening during an ultrasound for her next pregnancy:

> *"I said to my husband like, 'Is there a baby there?', you know? And he said, 'Oh yeah, there's a baby there!' And I'm like, 'Does it look like as far as you can understand ultrasounds, do you see arms, legs, the head?'... like I have no idea, right? Whereas a sighted person can see the screen."*

Many people with disabilities had to undertake considerable self-advocacy as well. Jennifer, who has rheumatoid arthritis, described how challenging this could be:

> *"I do recall being the person to do a lot of calling and appointment making and seeking out supports. I mean, I think it was a challenge to try to coordinate everything myself, which I guess is somewhat of a barrier, but you know, the kind of person I am, I'm able to advocate for myself. But I can very well see someone else who would not be able to necessarily advocate for themselves in the same way."*

FINDINGS

EXPERIENCES OF PEOPLE WITH DISABILITIES

Flexible care strategies

Several people with disabilities also described how having pregnancy care that could be delivered in a flexible way was especially helpful. For example, receiving pregnancy care in their own home removed many barriers to care for people with disabilities. This made midwifery models of care appealing to several participants, including Siobhan:

"When you're home with the midwives, you're totally levelling the playing field. I'm in my own space so I know where everything is. I needed so many fewer accommodations… No one has to tell me how I can find the washroom… I loved that the midwives do home visits… I loved anytime I could get home visits, so helpful… There's also automatically more time to do any of that learning or asking questions."

Adapted and hands-on help

People with disabilities noted how service-providers were most helpful when they were able to adapt care strategies to suit their unique needs. This often included providing "hands-on" help, which was particularly useful for breastfeeding and newborn care. Siobhan, for example, reported receiving support from a helpful independent skills worker with her first child:

"My Canadian National Institute for the Blind independent skills worker actually walked me through how to change a diaper. It does help to have someone really take the time to show you how to do it, not just, 'Watch this video on how to change a diaper,' you know? But more like, 'Feel this, this is the diaper. This is how you can feel the flaps, this is the back, this is the front.' That was good."

FINDINGS

EXPERIENCES OF SERVICE-PROVIDERS AND DECISION-MAKERS

Challenges to high-quality pregnancy care

Common challenges in pregnancy care for people with disabilities identified by service-providers and decision-makers were:

1. **Inflexible fee-for-service remuneration policies;**
2. **Inadequate education and training; and**
3. **Limited resources.**

Inflexible fee-for-service remuneration policies

Several service-providers described the policies and structures that made delivery of accessible pregnancy care challenging. For example, many service-providers noted that Ontario's fee-for-service remuneration policies, wherein most physicians are paid a fee for each specific service they provide, disincentivize physicians from allocating sufficient time to appointments. One of the obstetrician-gynecologists we interviewed shared:

> *"There's a pie. It's this big and you don't suddenly get extra time… So if you're spending more time on this, it means less time you're spending on other things… I hate to say it's a barrier, but you don't get paid for the time, right? So, I see the patient, it's taking up all the time, I can't see anyone else during that time, and I get paid $45, out of which I also have to pay my assistant's time and everything else. So, it's kind of a bit of pro bono work… So, there has to be some sort of recognition of funding for that as well. It's not a five-minute assessment, it's much longer than that."*

Similar challenges were identified by decision-makers. For example, a provincial policy maker commented: *"The way that the system works, it disadvantages people who may need extra supports. And so providers are not likely to want to take on any patient that they see as complex."*

EXPERIENCES OF SERVICE-PROVIDERS AND DECISION-MAKERS

Inadequate education and training

Like people with disabilities, many health and social service-providers themselves shared that they received little to no formal disability-related training, and that this impeded their ability to provide high-quality pregnancy care to people with disabilities. For example, an obstetrician-gynecologist described her prior experience as an occupational therapist and how that differed significantly from her later experience as a medical student:

"So, I think because I was an occupational therapist and because I spent a lot of time working with clients and families who were caregivers of people with disabilities, obviously that was my initial interesting background. And then, as I went into medicine, it was an area that I sort of felt we got no exposure to at all and it wasn't really discussed or anything that people had training in."

A midwife also explained that social service-providers often do not receive sufficient disability-related training, and what the implications of this lack of education are for how they think about people with disabilities and their ability to parent: *"It's very true that folks at child welfare aren't given much training [about disability] at all, so their personal assumptions will also come into play a fair amount."*

A number of service-providers also pointed out how a lack of training on disability was a gap in the broader diversity, equity and inclusion training they received. For example, a child welfare provider shared his experience: *"We have an anti-oppression, anti-racism framework and we receive training probably once every two years… I would say that there's not a focus at all on disability training in our workplace."*

Many participants recognized that a lack of disability education and training has negative impacts on pregnancy care delivery. For example, several decision-makers commented about how inadequate knowledge about disability results in a narrow view of what accessibility means. A child welfare services director commented:

"We need to get past that notion that disability just means you're in a wheelchair, versus you know, it can be anything right, whatever type of disability. So ensuring we have large print and ensuring we have – when you come into our office, we have braille on elevators and so on, ensuring you're knowing where you're going. So yeah. I must tell you though, we have to work at that, we really have to work at that."

Limited resources

Additionally, both health and social service-providers commented that a lack of resources was a critical challenge in providing high quality pregnancy care to people with disabilities. For example, they felt they had limited physical infrastructure to make pregnancy care accessible. An obstetrician-gynecologist noted:

"…resources are always a challenge. And resources being space, ultrasound availability, nursing care, coordinator care…"

A few service-providers further described how this lack of resources directly impacted accessibility. An obstetrician-gynecologist shared: *"I don't have wired lifts or some of the sophisticated things you'll see at tertiary care hospitals. And at my hospital, really no support. It's just I'm given the clinic space."*

Likewise, service-providers felt they had limited resources to make communication accessible. For example, a primary care nurse practitioner shared:

"We do not have braille on our signage, and then for hearing impairment, I'm not too sure what we could do for them other than speak clearly so they could read our lips."

FINDINGS

EXPERIENCES OF SERVICE-PROVIDERS AND DECISION-MAKERS

Facilitators of high-quality pregnancy care

Facilitators of high-quality pregnancy care for people with disabilities identified by service-providers and decision-makers include:

1. **Policy changes to improve access;**
2. **Service-provider advocacy for their patients;**
3. **Holistic care; and**
4. **Tailored care.**

Policy changes to improve access

Many service-providers and decision-makers recognized that the current policies in place create multiple barriers to pregnancy care for people with disabilities and accordingly noted that system-level change is necessary to improve access to high-quality pregnancy care for this population. For example, a social worker explained:

“I mean there’s so much that’s broken with the system. There needs to be much broader organization and communication within agencies. Cooperation within those agencies. Some of our biggest fights happen with agencies who are supposed to be doing similar work in terms of supporting families and they’re declining to support families and excuses, ‘Oh the Ministry needs X, Y and Z to happen.’ They demand that parents jump through unreasonable hoops to access their services when it’s just a complete lack of clinical understanding of what families are experiencing and the struggles that they’re having.”

Service-provider advocacy for patients

Similar to what was shared by people with disabilities, many service-providers expressed that it is important for service-providers to advocate for the disability-related needs of their patients, particularly to ensure they have the accommodations they need during pregnancy care. For example, a midwife explained:

“Advocacy and making sure you have figured it all out and you’ve touched base with people with different qualifications… The social worker department, make them find resources. Child welfare, demand to know what they’re going to need to see to be convinced that this person can parent. Have it all in writing… Every time, that person deserves to have wrap-around care that is prepared, informed, and proactive.”

Similarly, a social worker shared that service-providers in a similar role as them should advocate to reduce existing barriers to pregnancy care for people with disabilities:

“So, definitely someone who pushes the barrier. Someone who’s definitely not complacent to the systems that they interact with, including their own internal systems, but someone who really pushes against those preconceived notions and the status quo… I make some friends, but I may have made a few more enemies than friends and that’s okay because that’s sometimes what the work requires.”

FINDINGS

EXPERIENCES OF SERVICE-PROVIDERS AND DECISION-MAKERS

Holistic care

A few health care providers shared that holistic care that considers both the medical and social needs of people with disabilities is crucial for high-quality pregnancy care for people with disabilities. For example, a family physician, who provides low-risk obstetric care, shared:

"I just think we need to sort of have more holistic care, you know? Maternity care is not about just, you know, checking on the heartbeat, blood pressure, they're fine and they're out the door. Like, I think you need to think about the whole person, about their social situation, what's happening, how is it going to look after they have their baby, and anticipate certain things, you know? So, you just have to really look at the whole, you know, social situation around this pregnancy."

Tailored care

Several service-providers noted that pregnancy care needs to be tailored to individuals' unique needs. For example, a social worker described how pregnancy care cannot be "one size fits all": *"I just see some of the programs and things we have for [people with disabilities], and it doesn't work for everyone, and we need to offer specific things for specific groups because everyone's different."*

Several service-providers also shared that it was critical for them to have access to specific disability-related services to ensure they can properly meet their patients' disability-related needs. A midwife described:

"So, whenever somebody is having – who is d/Deaf and having a child either in hospital or out – I always make sure there's – and I make this distinction purposefully – a professional American Sign Language interpreter present. The Ontario government is required to pay for an American Sign Language interpreter. You can't write shit down, you can't just yell louder, and you can't ask a family member to interpret, they're too involved in the birth."

A family physician with expertise in developmental disabilities further explained the importance of adapting her communication style to the needs of her patients:

"I think communication is really important and can easily, with not having a lot of time, you can rush through explaining, whether it's the education part of prenatal care or what you can't eat, what you can't do, or even just explaining the tests… But I think it's helped me to communicate clearly with all my patients. Just the need to be really explicit and concrete with women with developmental disabilities."

DISCUSSION

CHALLENGES IN AND FACILITATORS OF PREGNANCY CARE

Based on our data, people with disabilities in Ontario experience many challenges in pregnancy care, including accessibility barriers, fragmented care across services, poor service-provider knowledge, lack of respect from service-providers, ableist service-provider assumptions, and inadequate information and decision-making autonomy. On the other hand, their identified facilitators included advocacy, adapted and hands-on help, and flexible care strategies. Likewise, service-providers and decision-makers in Ontario reported challenges related to inflexible fee-for-service remuneration policies, inadequate education and training, and limited resources, with facilitators including policy changes to improve access, service-provider advocacy for their patients, holistic care and tailored care. These findings are consistent with prior studies, mostly from the US.[4-23]

The reasons for challenges to pregnancy care for people with disabilities are complex, and ultimately relate to the ableism that is entrenched in the health care system. As described in Chapter 1, eugenic practices were the norm in Canada throughout much of the 20th century and were endorsed by the Canadian Medical Association.[24] While involuntary sterilization laws targeting people with disabilities were repealed in the 1970s,[25] ableist societal perceptions toward disability, sexuality, pregnancy and parenting persist today. These systemic issues have a “trickle down” effect on health care, resulting in the de-prioritization of disability-related education and training for health care providers, and a lack of resources to enable them to provide equitable and inclusive pregnancy care.

IMPLICATIONS FOR POLICY AND PRACTICE

The experiences of people with disabilities, service-providers and decision-makers outlined in this chapter are important to understand in parallel with the disparities in health-related outcomes described in the previous chapters. Together, these findings have important implications for the creation of pregnancy care policies and clinical practices that meet the needs of people with disabilities. These are outlined in detail in Chapter 7.

DATA NEEDS

Several limitations should be considered when interpreting the findings presented in this chapter:

- Although we interviewed 31 people with disabilities and 31 service-providers and decision-makers, some diverse perspectives may not be reflected in our interviews. For example, we did not ask about the dual impacts of ableism and other forms of oppression, such as racism and heterosexism, on people’s experiences.
- Our interviews were conducted prior to the COVID-19 pandemic. It is possible that the pandemic impacted the pregnancy care experiences of people with disabilities in ways that might inform future care recommendations.

FUTURE RESEARCH

Several avenues for future qualitative research could help to inform policy and clinical practice related to pregnancy care for people with disabilities, including:

- Studies to develop content for evidence-based service-provider curricula in professional degree programs and continuing education activities; and
- Studies to develop content for accessible informational resources for pregnant people with disabilities.

The results of this additional research could be used to improve the quality of pregnancy care for disabled people.

Conclusion

People with disabilities in Ontario experienced numerous challenges in pregnancy care, including accessibility barriers, fragmented care across services, poor service-provider knowledge, lack of respect from service-providers, ableist service-provider assumptions, and inadequate information and decision-making autonomy. Pregnancy care experiences were made more positive for people with disabilities through advocacy, flexible care strategies and adapted and hands-on help. Likewise, service-providers and decision-makers identified inflexible fee-for-service remuneration policies, inadequate education and training, and limited resources as challenges to the delivery of pregnancy care for people with disabilities, but identified the benefits of policy changes to improve access, service-provider advocacy for their patients, holistic care and tailored care. These data show more needs to be done to improve the quality of pregnancy care for disabled people.

Related publications

- Khan M, Brown HK, Lunsky Y, Welsh K, Proulx L, Havercamp S, et al. A socio-ecological approach to understanding the perinatal care experiences of people with intellectual and developmental disabilities in Ontario, Canada. *Womens Health Issues* 2021; 31(6):550–9.
- Tarasoff LA, Lunsky Y, Welsh K, Havercamp S, Vigod SN, Brown HK. The disability-related education and training experiences of perinatal care providers in Ontario. *J Obstet Gynaecol Can* 2023; 45(8):581–6.
- Tarasoff LA, Lunsky Y, Welsh K, Proulx L, Havercamp SM, Parish S, et al. Unmet needs, limited access: a qualitative study of postpartum health care of people with disabilities in Ontario, Canada. *J Adv Nursing* 2023; 79(9):3324–36.
- Saeed G, Brown HK, Lunsky Y, Welsh K, Proulx L, Havercamp SM, et al. Barriers to and facilitators of effective communication in perinatal care: a qualitative study of the experiences of people with sensory, intellectual, and/or developmental disabilities. *BMC Preg Childbirth* 2022; 22(1):364.

RETURN TO PREVIOUS PAGE

References

1. Sword W, Heaman MI, Brooks S, Tough S, Janssen PA, Young D, et al. Women's and care providers' perspectives of quality prenatal care: a qualitative descriptive study. *BMC Preg Childbirth* 2012; 12:29.
2. Rush J. *Family-Centred Maternity Care Scoring Tool Project: Phase II: Obtaining Parent Input.* Toronto: Ontario Ministry of Health, Institutional Services Branch, Maternal and Newborn Initiatives; 1997.
3. Public Health Agency of Canada. *Family-Centred Maternity and Newborn Care: National Guidelines.* Ottawa: PHAC; 2017.
4. Walsh-Gallagher D, Sinclair M, McConkey R. The ambiguity of disabled women's experiences of pregnancy, childbirth, and motherhood: a phenomenological understanding. *Midwifery* 2012; 28(2):156–62.
5. Heideveld-Gerritsen M, van Vulpen M, Hollander M, Oude Maatman S, Ockhuijsen H, van den Hoogen A. Maternity care experiences of women with physical disabilities: a systematic review. *Midwifery* 2021; 96:102938.
6. Tarasoff LA: "We don't know. We've never had anybody like you before": barriers to perinatal care for women with physical disabilities. *Disabil Health J* 2017, 10(3):426–33.
7. Mitra M, Long-Bellil LM, Iezzoni LI, Smeltzer SC, Smith LD. Pregnancy among women with physical disabilities: unmet needs and recommendations on navigating pregnancy. *Disabil Health J* 2016; 9(3):457–63.
8. Smeltzer SC, Mitra M, Iezzoni LI, Long-Bellil L, Smith LD: Perinatal experiences of women with physical disabilities and their recommendations for clinicians. *J Obstet Gynecol Neonatal Nurs.* 2016; 45(6):781–9.
9. Iezzoni LI, Wint AJ, Smeltzer SC, Ecker JL. Physical accessibility of routine prenatal care for women with mobility disability. *J Womens Health* 2015; 24(12):1006–12.
10. Powell RM, Mitra M, Smeltzer SC, Long-Bellil LM, Smith LD, Rosenthal E, et al. Breastfeeding among women with physical disabilities in the United States. *J Hum Lact* 2018; 34(2):253–61.
11. Williams D, Webber J, Pell B, Grant A, Sanders J, Choy E, et al. "Nobody knows, or seems to know how rheumatology and breastfeeding works": women's experiences of breastfeeding whilst managing a long-term limiting condition – a qualitative visual methods study. *Midwifery* 2019; 78:91–6.
12. Mercerat C, Saïas T. Parents with physical disabilities and perinatal services: defining parents' needs and their access to services. *Disabil Soc* 2020: 36(8):1261–84.
13. Mitra M, Smith LD, Smeltzer SC, Long-Bellil LM, Sammet Moring N, Iezzoni LI. Barriers to providing maternity care to women with physical disabilities: perspectives from health care providers. *Disabil Health J* 2017; 10(3):445–50.
14. Hubbard LJ, D'Andrea E, Carman LA. Promoting best practice for perinatal care of Deaf women. *Nurs Womens Health* 2018; 22(2):126–36.
15. Gichane MW, Heap M, Fontes M, London L: "They must understand we are people": pregnancy and maternity service use among signing Deaf women in Cape Town. *Disabil Health J* 2017; 10(3):434–9.
16. Mazurkiewicz B, Stefaniak M, Dmoch-Gajzlerska E. Perinatal care needs and expectations of women with low vision or total blindness in Warsaw, Poland. *Disabil Health J* 2018; 11(4):618–23.
17. Frederick A. Between stigma and mother-blame: blind mothers' experiences in USA hospital postnatal care. *Soc Health Illness* 2015; 37(8):1127–41.
18. Höglund B, Larsson M. Struggling for motherhood with an intellectual disability—a qualitative study of women's experiences in Sweden. *Midwifery* 2013; 29(6):698–704.
19. Potvin LA, Brown HK, Cobigo V. Social support received by women with intellectual and developmental disabilities during pregnancy and childbirth: an exploratory qualitative study. *Midwifery* 2016; 37:57–64.
20. Khanna A, Smith LD, Parish SL, Mitra M. Pregnancy recommendations from women with intellectual and developmental disabilities to their peers. *Disabil Health J* 2022; 15(4):101343.
21. Smeltzer SC, Mitra M, Long-Bellil L, Iezzoni LI, Smith LD. Obstetric clinicians' experiences and educational preparation for caring for pregnant women with physical disabilities: a qualitative study. *Disabil Health J* 2018; 11(1):8–13.
22. Amir N, Smith LD, Valentine AM, Mitra M, Parish SL, Moore Simas TA. Clinician perspectives on the need for training on caring for pregnant women with intellectual and developmental disabilities. *Disabil Health J* 2022; 15(2):101262.
23. Smith LD, Valentine A, Moore Simas TA, Parish SL, Levy A, Mitra M. Clinician-reported barriers to providing perinatal care to women with intellectual and developmental disabilities. *J Intellect Dev Disabil* 2023; 48(1):12–22.
24. de Bruin T, Robertson G. Eugenics in Canada. *The Canadian Encyclopedia;* 2019. Accessed November 2, 2022. https://www.thecanadianencyclopedia.ca/en/article/eugenics
25. Grekul J. The right to consent? Eugenics in Alberta, 1928–1972. In: Miron J, editor. *A history of human rights in Canada: essential issues.* Toronto: Canadian Scholars' Press; 2009; p. 135–54.

07

Equity and Inclusion in Pregnancy Care: Conclusion

MAIN MESSAGES

- **This Report provides an overview of preconception, pregnancy, labour and birth, and postpartum and newborn health outcomes among 147,622 births to disabled females between 2010/11 and 2019/20, in parallel with the perspectives of 31 people with disabilities and 31 service-providers and decision-makers on challenges to and facilitators of pregnancy care for people with disabilities.**
- **Our findings show important preconception, pregnancy, labour and birth, and postpartum and newborn health disparities in females with versus without disabilities that signal the need for high-quality pregnancy care for people with disabilities.**
- **Interviews with people with disabilities as well as service-providers and decision-makers reveal gaps in the quality of care, and in policies and resources to support high-quality pregnancy care.**
- **Our findings show the need for action to improve equity and inclusion in pregnancy care for people with disabilities.**
- **These actions include modifying health care system structures and processes, increasing service-provider knowledge and resources, developing accessible patient supports, and strengthening the scientific evidence base.**

Introduction

This Report describes preconception, pregnancy, labour and birth, and postpartum and newborn health outcomes in 147,622 births to disabled females in Ontario, 2010/11–2019/20, in parallel with the pregnancy care experiences of 31 people with disabilities and 31 service-providers and decision-makers. This is the most comprehensive study in the world and the first Canadian study of this scale on pregnancy in people with disabilities.

- **Chapter 2** established that disability is common in reproductive-aged females, that females with disabilities are more likely than those without disabilities to experience preconception health disparities, and that one in eight pregnancies in Ontario are to females with a disability.
- **Chapter 3** showed that most disabled females have timely and frequent access to prenatal care and healthy pregnancies, but there are important disparities in hospital care, physical and mental health, and experiences of interpersonal violence in pregnancy, particularly for those with developmental and multiple disabilities.
- **Chapter 4** showed that there are small differences in rates of labour and delivery interventions in females with versus without disabilities, and that females with disabilities and their newborns have longer hospital stays, and disparities in preterm birth, small for gestational age, and breastfeeding initiation and support.
- **Chapter 5** showed that most disabled females have timely access to routine postpartum care and are healthy postnatally, but that there were important disparities in hospital care, physical and mental health, and experiences of interpersonal violence in females with disabilities in the postpartum period, and in intensive care unit admission in their newborns, particularly for females with developmental and multiple disabilities.
- Throughout each chapter, personal stories of people with disabilities, service-providers, and decision-makers highlighted factors that contribute to these disparities and recommendations to address them. In **Chapter 6**, the experiences of people with disabilities, service-providers, and decision-makers in the context of pregnancy care were further explored, showing challenges to and facilitators of high-quality pregnancy care.

Overall, our findings show that Canada's goal of providing high-quality pregnancy care to all families has yet to be realized in the health outcomes and health care experiences of people with disabilities.

PUTTING IT ALL TOGETHER

In Chapter 1, we identified existing initiatives that should be built upon to improve pregnancy care for people with disabilities. These include clinical guidelines such as the Society of Obstetricians and Gynaecologists of Canada's Guideline No. 416: "Labour, Delivery, and Postpartum Care for People with Physical Disabilities"[1] and the 2018 Canadian Consensus Guidelines for Primary Care of Adults with Intellectual and Developmental Disabilities,[2] which were released during the Disability and Pregnancy Study and are based partly on the data we generated. Other initiatives include the handful of accessible pregnancy care clinics in Ontario and British Columbia.[3] However, these are the exception rather than the rule, leaving many patients and service-providers to search for resources in a fragmented health care system that does not routinely address disability-related needs.

In this final chapter, informed by the recommendations of our key informant groups, we propose several actions that are needed to embed initiatives like these into the regular delivery of care. These actions include the need to:

1. **Modify health care system structures and processes;**
2. **Increase health care provider knowledge and resources;**
3. **Develop accessible patient supports; and**
4. **Strengthen the scientific evidence base.**

We note that although such actions certainly carry a cost to the health care system, they are aimed at improving the quality of pregnancy care so that costly complications, including the complications related to physical and mental health that we observed among people with disabilities in pregnancy and postpartum, can be avoided. These actions to improve pregnancy care will ultimately support people with disabilities and the next generation.

PUTTING IT ALL TOGETHER

MODIFY HEALTH CARE SYSTEM STRUCTURES AND PROCESSES

Our Report shows that, although many people with disabilities have safe and healthy pregnancies, the current pregnancy care system is frequently fragmented and inaccessible. There is a clear need to modify the structures and processes of pregnancy care so that it meets the needs of all disabled people. Specific actions include ensuring pregnancy care spaces and resources are accessible to disabled people; adapting pregnancy care guidelines and physician remuneration policies; providing person-centred, multidisciplinary care; providing disability-affirming care; and applying a life course perspective to health care for people with disabilities. Across these health care system changes, it is critical that people with lived experience of disability are engaged.

Ensure pregnancy care spaces, resources, and technology are accessible to disabled people

Pregnancy care spaces, resources and related technology should be accessible to disabled people's mobility, communication, sensory and learning needs. Canada ratified the United Nations Convention on the Rights of People with Disabilities in 2010.[4] This legally obligates Canada to ensure people with disabilities have equal rights as those without disabilities related to health and health care access. However, Ontario's policies have fallen short of this requirement. A 2023 review of the Accessibility for Ontarians with Disabilities Act shows it is not likely to meet its goal of accessibility for Ontarians with disabilities by 2025, and the associated Healthcare Standards are still in the process of being considered by government as of the publication of this Report.[5]

Our interviews revealed numerous accessibility barriers for people with disabilities during pregnancy care, as well as barriers to their service-providers in delivering accessible care. For example, when asked what could be done to improve pregnancy care for disabled people, Johanna, who has limb girdle muscular dystrophy and osteoporosis, recommended the following about obstetric health care spaces:

> ***"Just be aware of how welcoming the office is to a disabled person. Even just little things like in the waiting room, is there a place to wait with a wheelchair? When [providers] actually listen, you'll hear them say, 'Oh, I'm glad you said that because now it's so much easier to transfer you this way.'"***

To improve pregnancy care for people with disabilities, all obstetric, midwifery and family medicine health care spaces should be accessible to people who use mobility devices; this includes having accessible weigh scales, examination tables and ultrasound machines. All health care providers should also be able to engage American Sign Language interpreters for patients. Likewise, patient resources should be available in alternative formats, such as electronic resources that can be used with a screen-reader, as well as simplified "easy read" resources with illustrations or photos to facilitate understanding and interpretation of information.

PUTTING IT ALL TOGETHER

MODIFY HEALTH CARE SYSTEM STRUCTURES AND PROCESSES

Adapt pregnancy care guidelines and physician remuneration policies

Pregnancy care guidelines and physician remuneration policies should be adapted to allow longer pregnancy care visits for people with disabilities, and at elevated frequency during critical periods, as needed. In Canada, prenatal care is typically structured around brief 10- to 15-minute office visits delivered at increasing frequency only in the second and third trimesters, while postpartum care with a physician is limited to one routine visit at six weeks after childbirth.[6] Recommendations for more frequent pregnancy care exist for some groups (e.g., people with cardiovascular disease).[7]

Our data showed that, with few exceptions, people with disabilities have similar timing and number of prenatal and postpartum care visits as those without disabilities. However, elevated rates of hospital care and physical and mental health complications in pregnancy and postpartum among disabled people suggest the current structure of pregnancy care is inadequate to address their needs. In our interviews, people with disabilities often identified how having more time with health care providers made a meaningful difference to their care. For example, Leah, who has a developmental disability, emphasized that service-providers should not *“rush you out of the room.”* Health care providers similarly described how more time was needed to clearly communicate and comprehensively address the needs of their patients with disabilities. One family physician commented on needing *“time to address their social context… thinking about what supports they might need.”*

Therefore, to improve pregnancy care for people with disabilities, pregnancy care guidelines should be developed to guide the optimal number and length of prenatal and postpartum care visits. For example, more frequent or longer visits early in pregnancy could be useful for enhanced screening for complications and organization of supports in preparation for childbirth and newborn care. Likewise, additional visits across the extended postpartum period may be useful for addressing the elevated risks of physical and mental health complications. Physician remuneration policies should be adapted to allow for this enhanced care, for example through unique billing codes for longer pregnancy care visits for people with disabilities and other high-risk groups.

PUTTING IT ALL TOGETHER

MODIFY HEALTH CARE SYSTEM STRUCTURES AND PROCESSES

Provide patient-centred multidisciplinary care

Person-centred multidisciplinary pregnancy care should be available to people with disabilities, as needed, with systems in place to coordinate such care. Multidisciplinary pregnancy care approaches have been proposed for people with pre-existing chronic conditions such as diabetes mellitus and cardiovascular disease,[8] and typically include a set of services that are planned, managed and delivered across several cooperating service-providers from different specialties. In person-centred care, the patient is actively involved in shared decision-making, and care plans are adapted to the needs of the patient as they evolve.[9]

Our population-based data showed people with disabilities experienced elevated risks of both physical and mental health complications in pregnancy and postpartum, and our interviews further showed they often had numerous providers involved in their pregnancy care, including disability specialists such as rheumatologists, and for people with developmental disabilities in particular, social service providers. However, with few exceptions, their care did not appear to be organized using a coordinated approach.

Luciana, who has Sjögren's Syndrome, rheumatoid arthritis and fibromyalgia, recognized the need for a person-centred, multidisciplinary approach to care:

"I just wish there was a true multi-disciplinary team… a truly cohesive circle of care, that if this person is pregnant and she has a chronic illness or disability, 'Okay I'm going to send her to this person, this person, that person,' and they would all kind of know about you."

Therefore, we recommend that multidisciplinary pregnancy care teams that place the needs of the patient at the centre of care be routinely available to people with disabilities. The structure of such care will depend on the needs of the individual. However, it could include multiple health care providers, or integration of health care providers with community supports such as disability services. Multidisciplinary care requires coordination across the service-providers involved in care. As described by Alyssa, who has cerebral palsy and scoliosis, there is a need for *"somebody who kind of follows your case throughout so you don't have to keep on reiterating the same information again and again. Somebody who can maybe be your advocate sometimes if that's needed, just so all your medical professionals will be on the same page."*

PUTTING IT ALL TOGETHER

MODIFY HEALTH CARE SYSTEM STRUCTURES AND PROCESSES

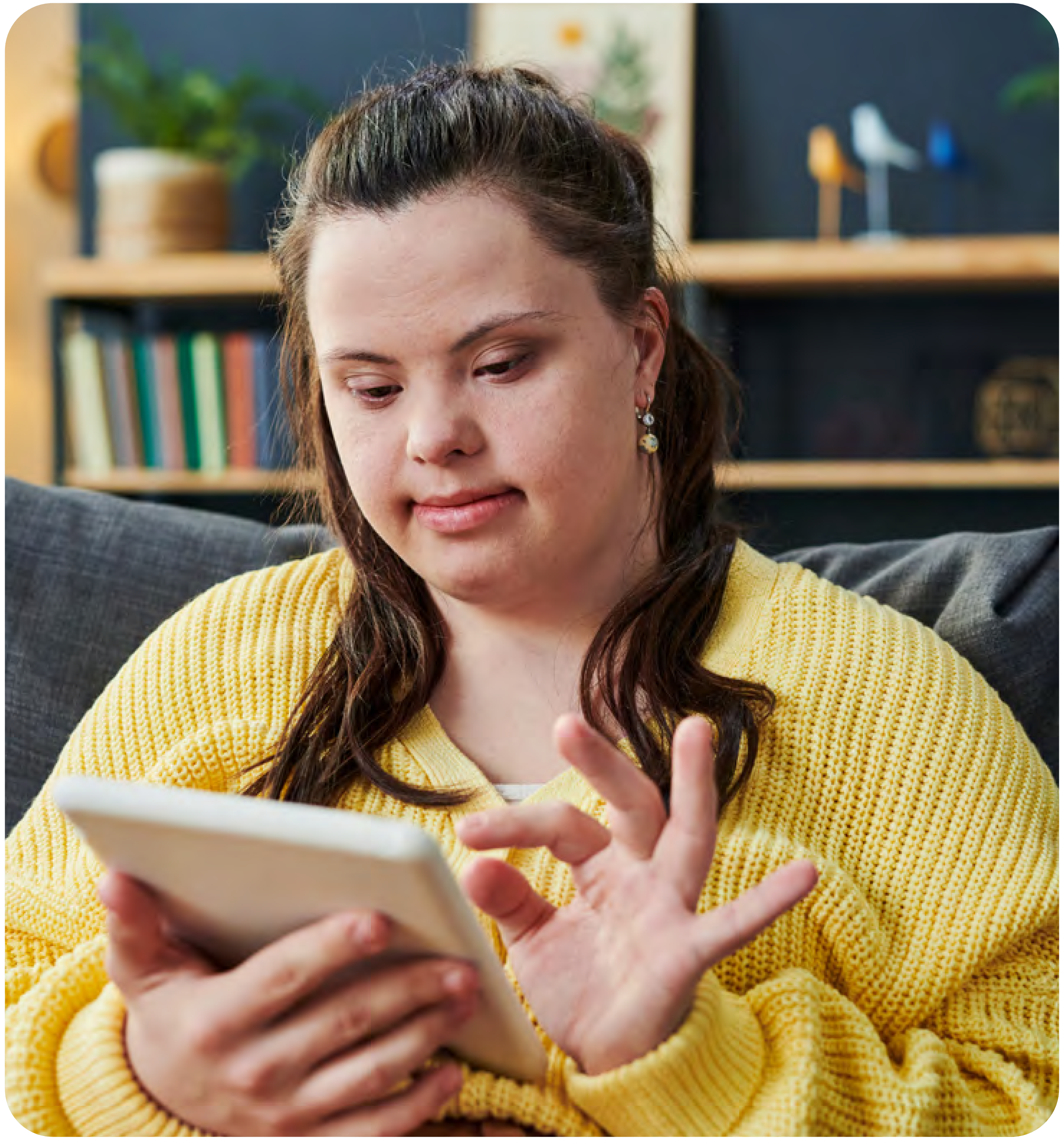
Provide disability-affirming services

Pregnancy care should also be affirming of people with disabilities. Disability-affirming care acknowledges the ableism and discrimination experienced by many disabled people and emphasizes access, self-determination and autonomy, validation of traumatic experiences, and cultural responsiveness in the delivery of care.[10] Although health care providers are increasingly acknowledging the importance of understanding and addressing trauma in pregnancy and postpartum care,[11] experiences of ableism and disability-based discrimination are typically not incorporated in such efforts.

In our interviews, Johanna commented how disability-affirming care would have been particularly helpful in the context of postpartum mental health care:

> ***"It would have been helpful to have some sort of mental health support or just support from other disabled people. Because I remember feeling very isolated and all the people I was seeing, they didn't get it. And I also was wary of appearing to struggle too much. So, if there was a way to have a safe person to share what you're struggling with... Maybe someone who actually sat you down and said, 'I know this is an issue with disability, I'm aware of it. These are the only instances that I would call child welfare.' I would have more trust if I knew the person was aware of that or were disabled themselves."***

Therefore, it is critical that pregnancy care take a disability-affirming stance, for example, by ensuring that care is accessible, acknowledging and addressing the impacts of ableism on patients' pregnancy care experiences, using language that the patient identifies as most accurate and respectful, and supporting patients in shared decision-making.[10] Promotion of disability-affirming pregnancy care within Ontario's health care system will require training of non-disabled service-providers and decision-makers in disability-affirming care approaches and policies, and supporting a workforce of service-providers and decision-makers who themselves have disabilities.[12]



PUTTING IT ALL TOGETHER

MODIFY HEALTH CARE SYSTEM STRUCTURES AND PROCESSES

Apply a life course perspective to health care for people with disabilities

More broadly, health care for people with disabilities should take a life course perspective that considers their reproductive health needs. Globally, there is increasing recognition that factors across the life course, including experiences and exposures before pregnancy, are critical for determining pregnancy-related health outcomes.[13] This recognition has led to advancements in preconception care, which emphasize the importance of health promotion for all individuals of reproductive age, regardless of their pregnancy intentions.[13] One component of preconception care is reproductive life plans, which are early conversations between health care providers and patients about if and when individuals plan to conceive, how to have a healthy pregnancy when they are ready, and how to avoid pregnancy if they want to.[14] However, health care for women with disabilities tends to focus on their disability, rather than broader health promotion and reproductive health care needs.

In our study, one of the obstetrician-gynecologists we interviewed reflected on the need to address ableist health care provider assumptions about the reproductive health needs of their disabled patients and to routinely provide reproductive health care:

> ***"I've seen this pendulum shift over 25 years because a lot of these women weren't getting pregnant before. [They] were being told that they needed to have their tubes tied or something, that they would have to have that done... So it's one of the questions that we ask when we see them, it's on the tick sheet: 'Are you sexually active?' And I think that's one of the things with the [medical] trainees working with me, that they're always a little surprised when they ask the question and the answer is 'yes.' Like why wouldn't we be asking? And [the trainees are] just like, "Oh, I just assumed,' but you can't make assumptions, right?"***

Therefore, to improve pregnancy care for people with disabilities, health care more broadly must address their reproductive health needs across the life course, including through accessible sexual health education, preconception care and reproductive life planning.

PUTTING IT ALL TOGETHER

MODIFY HEALTH CARE SYSTEM STRUCTURES AND PROCESSES

Engage people with lived experience of disability in health care system changes

Changes to health care system structures and processes require engaging with people with lived experience of disability. Research has shown that participatory approaches to policy and practice change create more sustainable change.[15]

However, many of the service-providers and decision-makers we interviewed noted that policy changes are often made with minimal or no engagement with disability communities.

For example, one public health nurse said:

> *"I think that higher up, the people higher up who make policies and all that need to actually come down to the frontline level and that's the only way people understand what needs to be done to support others. And it's just even in public health, new management who might have never had experience in public health, they have no idea of the work that we do and they just don't understand what the families need and what we need as public health nurses to do our job. So, I think, for me, the biggest thing would be don't just make policies up there, come and meet people that these policies are set for."*

We therefore recommend that across the health care system structure and process changes required, people with disabilities, disability advocacy organizations and service-providers with expertise in accessibility be consulted.

PUTTING IT ALL TOGETHER

INCREASE SERVICE-PROVIDER KNOWLEDGE AND RESOURCES

System-level changes require service-providers who are equipped to deliver high-quality pregnancy care to people with disabilities. However, inadequate service-provider education and training was a significant gap identified by people with disabilities, service-providers and decision-makers alike in the Disability and Pregnancy Study. There is thus a critical need to develop service-provider education and training related to disability and accessibility needs, ensure that such education and training addresses ableism and delivery of respectful pregnancy care, and develop clinical guidelines and other resources to support the delivery of pregnancy care, with people with disabilities actively involved in the creation of these resources and the delivery of training.

Develop service-provider education and training on disability and accessibility needs

All health and social service-providers should receive education and training about disability, accessibility needs and pregnancy care needs. Research shows early exposure of health care providers to people with disabilities and other equity-deserving groups during their training is critical for improving knowledge, confidence and attitudes in clinical settings.[16] However, most physicians, nurses and other service-providers receive little to no formal training related to disability in their initial or continuing professional education.[17] There is a growing focus on disability competency training in the US,[17] but similar efforts in Canada are limited and are often specific to faculty with particular expertise and interest at individual medical schools. Moreover, disability-related training does not typically address matters related to reproductive health and pregnancy.[17]

This is an important omission given that our population-based data showed that 16.3% of reproductive-aged females in Ontario have a disability, that one in eight pregnancies are to females with a disability, and that they have important health disparities in pregnancy and postpartum. Education and training of service-providers was identified as an important need by people with disabilities and service-providers in our interviews.

For example, a midwife said:

> ***“If somebody wants to be working with somebody within the disabled or d/Deaf community, I think they need to demonstrate they’ve done some training… And so, I think if there were certification training programs out there, then people, you know, within the d/Deaf or disabled communities would be able to say ‘Aah, this person’s done some training.’”***

We therefore recommend that all health and social service-providers receive education and training about disability, accessibility and pregnancy care needs. Such training can be integrated into multiple levels of education, for example broad education on disability, accessibility and sexual and reproductive rights in undergraduate training, and more specific education relevant to managing and supporting pregnancies in disabled people in post-graduate and continuing professional education for appropriate clinical groups. Given the growing focus on equity, diversity and inclusion training in medical schools and other professional degree programs, information on disability can also be integrated into such efforts.[18] This is critical given the intersecting forms of oppression often experienced by people with disabilities, such as ableism and racism or heterosexism.

PUTTING IT ALL TOGETHER

INCREASE SERVICE-PROVIDER KNOWLEDGE AND RESOURCES

Ensure training addresses ableism and delivery of respectful pregnancy care

Service-provider education and training should address ableism and delivery of respectful pregnancy care. Pregnancy care guidelines in Canada and elsewhere are increasingly emphasizing the importance of respectful pregnancy care, which ensures the rights of pregnant people to be treated with care, respect and dignity, and to maintain their autonomy.[19]

However, our interviews suggested significant shortcomings in pregnancy care for disabled people in this area. This issue was reflected in a recommendation for service-providers made by Alyssa, who has cerebral palsy and scoliosis: *"Make sure you're talking to the patient and not about the patient. Listen to their experiences – trust them when they say something."* One of the community nurses we interviewed reflected on how respectful care is particularly important in pregnancy, an impactful period in individuals' lives:

"I can only imagine how it goes down sometimes, in labour and delivery, for some of these individuals, that it could be quite challenging because it's such a fast-paced environment. And I know we hear from some of our patients who do not have disability that they feel judged and a little bit discriminated against. So, if you were to add on that [disability] and just a whole lack of understanding, I think it would be so important to somehow have some sort of – I don't know – sensitivity training for that group. Because, like, having a child – like it's been researched that that experience is ingrained on your brain forever, either bad or ugly, and so it can be so empowering if it's a good experience."

It is therefore critical that education and training for service-providers include training on the rights of people with disabilities to dignity, information and bodily and decision-making autonomy.

Develop clinical guidelines and other resources to support the delivery of pregnancy care

Clinical guidelines and other resources should be developed to support service-providers' delivery of pregnancy care to people with disabilities. Despite the growing body of research on disability and pregnancy, there are only a few evidence-based clinical guidelines on pregnancy care for people with disabilities.[1,2]

In our interviews, this paucity of information was recognized by service-providers and decision-makers alike, and the need for guidelines and resources that address diverse disability groups and span different pregnancy stages was strongly endorsed. Developing such a set of resources in Ontario might also include bringing together guidelines that are available in other jurisdictions. For example, several decision-makers commented on how having a central repository of resources would be helpful to facilitate delivery of pregnancy care to people with disabilities, drawing on the best evidence and practice leaders. This model can be especially helpful when a population is relatively small and resources for individual service-providers may be limited.

For example, one provincial policy maker shared:

"I think we do try to come up with creative solutions. We often use like a hub and spoke [model] when a population is small, across the province, and the extra piece is limited. We try to come up with… a hub somewhere where they're doing this really well, can they, can we gather some spokes around the province that they can sort of 'up' skill, and share information and become a little bit of a centre of that work? And that's sometimes how we work around some of these challenges…"

We therefore recommend that in conjunction with improved education and training for service-providers that data from our research and others should be collated in formal resources for service-providers, in the form of clinical guidelines and central lists of resources and clinical experts who can be consulted as needed.

PUTTING IT ALL TOGETHER

INCREASE SERVICE-PROVIDER KNOWLEDGE AND RESOURCES

Actively involve people with disabilities in the creation and delivery of service-provider training

As in activities at the policy level, it is critical that training and resources for service-providers reflect the needs and experiences of people with disabilities.

However, our interviews with service-providers suggested that, when they did receive disability-related training, people with disabilities were not often involved, or were involved in limited ways. For example, one physician commented:

> *"The training that goes on… they use standardized patients, it's gross… And all situations where you have abled persons designing the curriculum, or even worse, abled actors. Even when you have a standardized patient that has a disability, they don't get to talk about their lived experience. They are actors who do the role that the director or designer wants, it's gross."*

We therefore recommend that service-provider training and resources be developed in collaboration with people with lived experience of disability to ensure that the content addresses the needs of people with disabilities. Training could also be co-delivered by people with disabilities to offer important opportunities for service-providers to practice clinical skills, receive feedback and reflect on their learning.[20]

PUTTING IT ALL TOGETHER

DEVELOP ACCESSIBLE PATIENT SUPPORTS

Ultimately, actions at the system and provider levels should be aimed at improving direct patient supports, with the goal of reducing health disparities. Actions include developing tailored patient resources on disability and pregnancy, ensuring routine pregnancy-related education is accessible, and supporting community organizations in providing other supports to people with disabilities in pregnancy and postpartum, with these patient resources developed in direct consultation with people with disabilities.

Develop tailored resources on disability and pregnancy

Evidence-based resources related to disability and pregnancy, including resources for people planning a pregnancy and who are pregnant or postpartum, should be developed to meet patient-identified needs for information. Informed decision-making is a critical aspect of health care practice, including pregnancy care, and provision of information is critical for supporting such decision-making.[21]

However, in our interviews, a lack of information was a critical gap in pregnancy care identified by people with disabilities and service-providers alike, which meant people with disabilities often had many unanswered questions and fears about pregnancy. For example, Jennifer, who has rheumatoid arthritis, commented that she “always felt that [her health care providers] were trying to make the best decisions or trying to give the best advice they could, given the information they had,” but felt she would have benefited from access to tailored resources about disability and pregnancy. Likewise, a disability program director commented on the utility of a central repository of pregnancy resources:

> ***“I always say that if we all have a booklet of a place then the people can go. It’s a simple thing but nobody has thought about how to put those resources that people can just [pick up one and say] ‘If I need this help, where can I go? If I need a caregiver or I need a clinician, if I need a nurse practitioner, I need a midwife… And I need some kind of assistive devices to take care of my child, where should I go?’”***

To support informed decision-making among people with disabilities, there is a need to develop tailored resources that include information on pregnancy outcomes in people with disabilities, how pregnancy might impact disability-related symptoms and progression, and what to expect during pregnancy care. Such resources could be created for different disability groups with appropriate accessibility considerations (e.g., simplified “easy read” resources for people with developmental disabilities) and should include evidence-based information on different stages of pregnancy, including the preconception, pregnancy, labour and delivery, and postpartum and newborn periods.

Ensure routine pregnancy-related education is accessible

Routine pregnancy-related education, including prenatal, breastfeeding and newborn care classes, should be accessible to people with disabilities, and address their needs. Prenatal education, and breastfeeding and newborn supports, are important resources for patients and their partners and are associated with decreased stress and anxiety and improved clinical outcomes such as breastfeeding rates.[22,23]

As shown in our interviews, many people with disabilities attended prenatal classes and other forms of pregnancy-related education, but did not feel that these classes met their needs. For example, Johanna, who has muscular dystrophy, described her frustration with a newborn first aid class that she took:

> ***“Sometimes I was frustrated because the first aid [class], for example, I couldn’t physically do some of the things that they were telling us to do. And I’d be like, ‘How do I do this?’ … They wouldn’t really know how to advise me, and I was just like, ‘I don’t just want to let my baby die,’ you know?”***

Therefore, it is important that pregnancy-related education be accessible to people with disabilities. This includes designing physically accessible educational spaces for all, considering alternative ways of delivering pregnancy-related education, and actively offering accommodations.

PUTTING IT ALL TOGETHER

DEVELOP ACCESSIBLE PATIENT SUPPORTS

Provide other community-based supports

Community organizations should be supported to provide practical resources to people with disabilities planning a pregnancy or in pregnancy and postpartum. These resources are critical to help prospective and new parents with disabilities in their transition to parenting.[24]

In our interviews, many people with disabilities noted the value of disability advocacy organizations and allied health professionals, such as occupational therapists, in helping with practical tasks related to breastfeeding and newborn care or helping them find specialized equipment. For example, Alyssa, who has cerebral palsy, noted how a non-profit disability organization that builds assistive devices was critical in making newborn care easier for her: *"Tetra Society helped design me wheelchair-accessible cribs with like locks and latches on them that could open up and I could drive my wheelchair underneath and put them to bed and latch it closed."*

We therefore recommend that community organizations be supported to connect parents with disabilities with these practical supports, and that the scope of work for social service-providers, like attendant care workers, be broadened to include assisting with newborn care-related tasks.

Consult with people with disabilities in relation to the creation of patient supports

All patient-facing supports and resources should be developed in collaboration with people with lived experience of disability. Several of the service-providers we interviewed commented on how valuable community expertise was in informing their delivery of pregnancy care. For example, one midwife commented:

> *"[Disability] communities themselves have been very generous… I'm willing to learn and 'OK, I don't know what you need but let's figure this out together. And I'm sorry, I haven't encountered this before… I apologize but I need you to help me learn.' I have learned so much from folks in these communities…"*

Such input needs to be formalized in the co-creation of patient-facing supports. We therefore recommend that tailored pregnancy resources for people with disabilities be created in collaboration with people with disabilities, and that people with disabilities be consulted on the accessibility of other routine pregnancy-related services such as prenatal, breastfeeding and newborn care classes.

PUTTING IT ALL TOGETHER

STRENGTHEN THE SCIENTIFIC EVIDENCE BASE

Underlying all of these efforts is the need to continue to strengthen the scientific evidence base to inform delivery of high-quality care, evaluate the impact of new initiatives, and ultimately hold health care systems accountable for the quality of pregnancy care delivered to people with disabilities. The Disability and Pregnancy Study met a need for data on disability and pregnancy in Canada. However, it also highlighted data gaps that must be addressed, such as routinely including disability indicators in health administrative data, developing patient-reported outcome and experience measures, and creating a national funding strategy for research on disability and health equity, including pregnancy-related health outcomes and care.

Routinely include disability indicators in health administrative data

Disability indicators should be routinely included in health administrative data so that pregnancy-related health outcomes in disabled populations can be monitored at a population level. As described in prior chapters of this Report, many existing studies on disability and pregnancy have relied on surveys that omit people with medical conditions or social circumstances that prevent research participation; our own research using health administrative data likely excluded people with disabilities whose diagnoses were not recorded in those datasets and ignores the environmental and social factors that create disability. This is an issue for planning and for evaluating innovative interventions that could benefit people with disabilities. When discussing this issue in our interviews, a provincial program director commented:

“It’s hard to set a baseline for things that we never thought to capture in the first place. And then you’re trying to work backwards… It’s tricky.”

There are promising advancements in this area. For example, in the US, linked hospital discharge records, birth and fetal death files, and survey data from the Pregnancy Risk Assessment Monitoring System allow comprehensive ascertainment of both obstetric outcomes and self-reported disability, and a new initiative by the National Institutes of Health and the Centers for Disease Control and Prevention is now expanding questions on disability in this survey.[25] In Canada, a linkage of health administrative data and social services data showed such linkages provide more complete ascertainment of disability than either data source alone.[26] These efforts serve as examples for the routine inclusion of disability indicators in administrative data in ways that are better aligned with models of disability that do not rely solely on medical diagnoses to identify disability status.

Our study shows the importance of using routinely collected health administrative data to monitor the pregnancy-related health outcomes of people with disabilities. However, to our knowledge, as of the publication of this Report, the Disability and Pregnancy Study is one of the only efforts of this kind in Canada. Researchers in other provinces could apply similar algorithms to study disability and pregnancy, generating cross-provincial comparisons of health disparities in this population. Organizations such as Health Data Research Network Canada, which supports multi-regional health data use, could also be leveraged for national studies on this topic.

PUTTING IT ALL TOGETHER

STRENGTHEN THE SCIENTIFIC EVIDENCE BASE

Develop patient-reported outcome and experience measures

Patient-related outcome and experience measures should be developed in consultation with people with disabilities and used to ensure that efforts to improve pregnancy care meet their needs. These measures provide a systematic means of monitoring quality of care and the impacts of new interventions on patients' self-assessed health outcomes and experiences while receiving care. While such measures have been developed for pregnancy care broadly, none consider the unique needs of people with disabilities.[27] There is a need to develop such measures in consultation with people with disabilities to ensure that efforts at the system, provider and patient levels to improve the quality of pregnancy care are responsive to the specific needs of people with disabilities.

Create a national strategy for research on disability and health equity

Finally, prioritization of disability in Canadian national funding strategies is needed. The Disability and Pregnancy Study was funded by a call from the US National Institutes of Health for research on disability and pregnancy. The National Institutes of Health also recently designated people with disabilities as a "health disparities population," which will result in the prioritization of more funding opportunities on health equity in people with disabilities, including pregnant people.[28] Likewise, the National Institute for Health and Care Research in the UK has a national strategy on autism and intellectual disability, which facilitates research on health outcomes in this population and subsequent health care innovations.[29] Canada also needs a strategy to fund research related to disability and health equity, including pregnancy, which will result in better data to inform clinical care and policy. Such funding could support research related to the social and structural determinants of pregnancy-related health disparities in people with disabilities, and the experiences of people with disabilities experiencing other forms of oppression, such as racism and heterosexism: areas of research still largely unaddressed.

Conclusion

Many people with disabilities in Ontario experience pregnancy, and many can have healthy pregnancy and birth outcomes. However, findings from the Disability and Pregnancy Study show that Ontario is not yet equipped to meet the needs of many pregnant people with disabilities and their families. Our parallel data from population-wide health administrative datasets and interviews with key informant groups show that it is time for action, with policy and clinical practice leaders coming together with people with disabilities and engaging the data to ensure that pregnancy care is inclusive of and equitable for all people with disabilities.

07 Equity and Inclusion in Pregnancy Care: Conclusion

RETURN TO PREVIOUS PAGE

References

1. Berndl A, Ladhani N, Wilson RD, Basso M, Jung E, Tarasoff LA, et al. Guideline No. 416: labour, delivery, and postpartum care for people with physical disabilities. *J Obstet Gynaecol Can*. 2021; 43(6):769–80.
2. Sullivan WF, Diepstra H, Heng J, Ally S, Bradley E, Casson I, et al. Primary care of adults with intellectual and developmental disabilities: 2018 Canadian consensus guidelines. *Can Fam Physician* 2018; 64(4):254–79.
3. Sunnybrook Health Sciences Centre. *Accessible care pregnancy clinic: about.* Accessed November 2, 2022. https://sunnybrook.ca/content/?page=accessible-care-pregnancy-clinic-about
4. United Nations. *Convention on the Rights of Persons with Disabilities.* Treaty series, 2515, 3. New York: United Nations General Assembly; 2006.
5. AODA Accessibility. *AODA Healthcare Standards.* Accessed December 5, 2023. https://www.aoda.ca/aoda-healthcare-standards/
6. Society of Obstetricians and Gynaecologists of Canada. *Healthy beginnings: guidelines for care during pregnancy and childbirth.* Ottawa: SOGC; 1998.
7. Davis MB, Arendt K, Bellow NA, Brown H, Briller J, Epps K, et al. Team-based care of women with cardiovascular disease through pregnancy and postpartum. *J AM Coll Cardiol* 2021; 77(14):1763–77.
8. Taylor C, McCance DR, Chappell L, Nelson-Piercy C, Thorne SA, Ismail KMK, et al. Implementation of guidelines for multidisciplinary team management of pregnancy in women with pre-existing diabetes or cardiac conditions: results from a UK national survey. *BMC Pregnancy Childbirth* 2017; 17:434.
9. Berntsen G, Hoyem A, Lettrem I, Ruland C, Rumpsfeld M, Gammon D. A person-centered integrated care quality framework, based on a qualitative study of patients' evaluation of care in light of chronic care ideals. *BMC Health Serv Res* 2018; 18:479.
10. Olkin R. Disability-affirmative therapy. In: Marini I, Stebnicki, MA, editors. *The professional counselor's desk reference.* Berlin: Springer Publishing Company; 2009. pp. 355–369.
11. Sperlich M, Seng JS, Li Y, Taylor J, Bradbury-Jones C. Integrating trauma-informed care into maternity care practice: conceptual and practical issues. *J Midwifery Womens Health* 2017; 62(6):661–72.
12. Gertsman S, Dini Y, Wilton D, Neilson S. Tackling barriers in Canadian medical school admissions for students with disabilities. *CMAJ* 2023; 195(44):E1512–6.
13. World Health Organization. *Meeting to develop a global consensus on preconception care to reduce maternal and childhood mortality and morbidity.* Geneva: World Health Organization; 2012.
14. Freda MC, Moos MK, Curtis M. The history of preconception care: evolving guidelines and standards. *Mat Child Health J* 2006; 10:43–52.
15. Eyre L, Farrelly M, Marshall M. What can a participatory approach to evaluation contribute to the field of integrated care? *BMJ Qual Saf* 2017; 26(7):588–94.
16. Arvizo C, Garrison E. Diversity and inclusion: the role of unconscious bias on patient care, health outcomes and the workforce in obstetrics and gynaecology. *Curr Opin Obstet Gynecol* 2019; 31(5):356–62.
17. Havercamp SM, Barnhart WR, Robinson AC, Whalen Smith CN. What should we teach about disability? National consensus on disability competencies for health care education. *Disabil Health J* 2021; 14(2):100989.
18. Janz HL. Ableism: the undiagnosed malady afflicting medicine. *CMAJ* 2019; 191(17):e478–9.
19. Miller S, Abalos E, Chamillard M, Cipponi A, Colaci D, Comande D, et al. Beyond too little, too late and too much, too soon: a pathway towards evidence-based, respectful maternity care worldwide. *Lancet* 2016; 388(10056):2176–92.
20. Minihan PM, Bradshaw YS, Long LM, Altman W, Perduta-Fulginiti S, Ector J, et al. Teaching about disability: involving patients with disabilities as medical educators. *Disabil Stud Quart* 2004; 24(4).
21. Yuill C, McCourt C, Cheyne H, Leister N. Women's experiences of decision-making and informed choice about pregnancy and birth care: a systematic review and meta-synthesis of qualitative research. *BMC Pregnancy Childbirth* 2020; 20:343.
22. Hong K, Hwang H, Han H, Chae J, Choi J, Jeong Y, et al. Perspectives on antenatal education associated with pregnancy outcomes: systematic review and meta-analysis. *Women Birth* 2021; 34(3):219–30.
23. Kehinde J, O'Donnell C, Grealish A. The effectiveness of prenatal breastfeeding education on breastfeeding uptake postpartum: a systematic review. *Midwifery* 2023; 118:103579.
24. Wint AJ, Smith DL, Iezzoni LI. Mothers with physical disability: child care adaptations at home. *Am J Occ Ther* 2016; 70(6):1–7.
25. Signore C, Davis M, Tingen CM, Cernich AN. The intersection of disability and pregnancy: risks for maternal morbidity and mortality. *J Womens Health* 2021; 30(2):147–53.
26. Lin E, Balogh R, Isaacs B, Ouellette-Kuntz H, Selick A, Wilton AS, et al. Strengths and limitations of health and disability support administrative databases for population-based health research in intellectual and developmental disabilities. *J Policy Pract Intellect Disabil* 2015; 11(4):235–44.
27. Dickinson F, McCauley M, Smith H, van den Broek N. Patient reported outcome measures for pregnancy and childbirth: a systematic review. *BMC Pregnancy Childbirth* 2019; 19:155.
28. National Institutes of Health. *NIH designates people with disabilities as a population with health disparities.* Bethesda: NIH; 2023. Accessed October 30, 2023. https://www.nih.gov/news-events/news-releases/nih-designates-people-disabilities-population-health-disparities
29. National Institute for Health and Care Research. 23/77 National Learning Disability and Autism Programme demand signalling – commissioning brief. Accessed January 9, 2024. https://www.nihr.ac.uk/documents/2377-national-learning-disability-and-autism-programme-demand-signalling-commissioning-brief/33573

Promising Practices and Resources

CLINICAL GUIDELINES

- American College of Obstetricians and Gynecologists Committee on Obstetric Practice. Committee Opinion No. 808: Obstetric management of patients with spinal cord injuries. *Obstet Gynecol* 2020; 135(5):e230–6.
- Berndl A, Ladhani N, Wilson RD, Basso M, Jung E, Tarasoff LA, et al. Guideline No. 416: Labour, delivery, and postpartum care for people with physical disabilities. *J Obstet Gynaecol* Can 2021; 43(6): 769–80.
- Sullivan WF, Diepstra H, Heng J, Ally S, Bradley E, Casson I, et al. Primary care of adults with intellectual and developmental disabilities: 2018 Canadian consensus guidelines. *Can Fam Physician* 2018; 64(4):254–79.

PROVIDER TRAINING RESOURCES

- Caring for pregnant and new parents with physical disabilities, BC Provincial Health Services Authority, Vancouver, BC: eLearning Course on health and breastfeeding considerations for pregnant and postpartum people with physical disabilities
- Supporting people with disabilities in pregnancy, labour and delivery, and postpartum: Resources for public health nurses, Public Health Nursing Practice, Research & Education Program, Hamilton, ON: Quality care essentials for public health nurses working with pregnant and postpartum people with disabilities
- Tailoring pregnancy care for people with disabilities: Resource for health care providers, Provincial Council for Maternal and Child Health, Toronto, ON: Resource for health care providers working with pregnant and postpartum people with disabilities
- The Advancing Care Excellence for Persons with Disabilities Program, National League for Nursing, Washington, DC: Resources and teaching strategies for nurses working with people with disabilities
- The National Center for Disability and Pregnancy Research, Heller School for Social Policy and Management, Brandeis University, Waltham, MA: Research and resources to improve the pregnancy experiences and outcomes of people with disabilities

Promising Practices and Resources

CLINICAL CENTRES WITH EXPERTISE

- Accessible Care Pregnancy Clinic, Sunnybrook Health Sciences Centre, Toronto, ON: Specialized clinic that provides care for people with physical disabilities who are pregnant or are contemplating a pregnancy
- Advanced Collaborative Care Planning Program, BC Women's Hospital and Health Centre, Vancouver, BC: Provides specialized pregnancy care to people with spinal cord injuries and other complex chronic conditions
- Pregnancy and Rheumatic Diseases Clinic, Mary Pack Arthritis Centre, Vancouver, BC: Provides pregnancy counselling to people with rheumatic diseases, including medication reviews before and during pregnancy

RESOURCES TO ASSIST WITH CARE DELIVERY

- Childbirth Preparation and Support Tool, Health Nexus, Toronto, ON: A tool for health care providers to use with patients with fetal alcohol spectrum disorder and related disabilities who may need extra support in the perinatal period
- Disabled Parents Network, London, UK: A national organization for disabled people who are parents or hope to become parents, and their families, friends and supporters
- Having a Baby, Books Beyond Words, London, UK: Easy-read stories for people with developmental disabilities about what is involved in being pregnant, becoming a parent and caring for a baby
- Loving Babies, Books Beyond Words, London, UK: Easy-read story for people with developmental disabilities about caring for a newborn
- Mamas Facing Forward: Private Facebook group designed to help women with chronic illness move forward with motherhood
- Mom on Wheels: The Power of Purpose for a Parent with Paraplegia, Ingenium Books, Toronto, ON: Biography of a parent with paraplegia
- Parenting with a Disability Network, Centre for Independent Living in Toronto, Toronto, ON: Cross-disability network for parents and prospective parents with disabilities
- Pregnancy and Postpartum Care: Resource for Parents with Disabilities, Provincial Council for Maternal and Child Health, Toronto, ON: Resource for people with disabilities planning a pregnancy
- Pregnancy and Spinal Cord Injury: An Information Booklet for Women with SCI, Vancouver Coastal Health's Sexual Health Rehabilitation Service, BC Women's Hospital and Health Centre's Maternal Fetal Medicine Service, Rick Hansen Institute, Spinal Cord Injury BC, Vancouver, BC: Resource for parents with spinal cord injuries
- Resources for Patients by Patients, Canadian Arthritis Patient Alliance, Ottawa, ON: Resources on sexuality, family planning, pregnancy and birth created by people with arthritis for people with arthritis

Technical Appendix

The Disability and Pregnancy Cohort: An Overview

The Disability and Pregnancy cohort is the result of a linkage of health administrative data on females in Ontario and their newborns over time. Within this cohort, we identified disability using a list of diagnoses that may indicate a physical, sensory or developmental disability, or multiple disabilities. Included diagnoses were based on an algorithm developed by our team to ascertain developmental disabilities,[1] and on algorithms to ascertain physical disabilities and sensory disabilities that were identified in a systematic literature review and evaluated by a group of 13 health care providers with disability expertise.[2,3]

Our final list of physical disabilities included congenital anomalies like spina bifida, musculoskeletal disorders like rheumatoid arthritis, neurological disorders like multiple sclerosis and permanent injuries like spinal cord injuries. Sensory disabilities included hearing and vision loss. Developmental disabilities included autism spectrum disorder, intellectual disability, chromosomal anomalies that result in intellectual disability like Down syndrome and fetal alcohol spectrum disorder.

USING HEALTH ADMINISTRATIVE DATA

Linked, anonymized health administrative data held at ICES were used for our analyses. ICES holds health administrative data in a controlled, anonymous manner that does not include any information that would allow individuals to be identified and that is compliant with Ontario's privacy legislation. ICES holds a registry of persons eligible to receive provincial health insurance benefits (the Registered Persons Database, RPDB) as well as data on outpatient physician visits (Ontario Health Insurance Plan, OHIP, database), emergency department visits (National Ambulatory Care Reporting System, NACRS) and hospital admissions (Canadian Institute for Health Information Discharge Abstract Database, CIHI-DAD and Ontario Mental Health Reporting System, OMHRS). These datasets were linked using a unique encoded identifier and accessed and analyzed at ICES.

Since our interest was in pregnancy, we first limited our cohort to all individuals whose sex was listed as female on their health card. This means that people who could become pregnant but had changed their health card identifier to "male" were excluded from our cohort (we therefore use the language of "female" when referring to the results from this cohort). We then limited the cohort to females aged 15 to 49 years. In Chapter 2, the cohort included all females in this age group, and in Chapters 3, 4, and 5, the cohort included females in this age group who had a singleton livebirth or stillbirth between 2010/11 and 2019/20. Births were ascertained by identifying the medical records of females giving birth in a hospital setting and their newborns, capturing 98% of births in Ontario.[4] All were required to be eligible for OHIP for at least two years before they entered the study cohort.

To identify females with disabilities, we looked back to the beginning of each database (that is, its inception date) for diagnostic codes related to physical, sensory and developmental disabilities. Some databases contain more than one field where diagnostic information can be recorded, and for these, we examined every field. An individual was considered to have a disability if they had:

- **Two or more physician visits (as recorded in OHIP) with a disability diagnosis, or**
- **One or more emergency department visits (as recorded in NACRS) with a disability diagnosis, or**
- **One or more hospital admissions (as recorded on CIHI-DAD or OMHRS) with a disability diagnosis.**

EXHIBITS

EXHIBIT A.1
DIAGNOSTIC CODES USED TO IDENTIFY PHYSICAL DISABILITIES IN HEALTH ADMINISTRATIVE DATA

Disability subtype	Condition	ICD-10 codes	ICD-9 codes	Other codes
Congenital anomalies	Congenital deformities of the spine (e.g., congenital scoliosis)	Q67.5	754.2	
	Congenital deformities of the feet (e.g., club foot)	Q66	754.5-754.7	OHIP: 754
	Congenital musculoskeletal deformities of the chest (e.g., congenital funnel chest)	Q67.6, Q67.7, Q67.8	754.8	
	Dwarfism, not elsewhere classified	E34.3	259.4	
	Hypopituitarism (e.g., pituitary dwarfism)	E23.0	253.4	
	Other congenital anomalies of the nervous system (e.g., congenital hydrocephalus)	Q01.9, Q02-Q04, Q06, Q07.8, Q07.9, G90.1	742	OHIP: 742
	Other congenital musculoskeletal deformities (e.g., osteochondroplasia)	Q75-Q79	756	OHIP: 756
	Reduction defects of lower limb	Q72	755.3	
	Reduction defects of unspecified limb (e.g., phocomelia NOS)	Q73, Q74	755.4	
	Reduction defects of upper limb	Q71	755.2	
	Spina bifida	Q05	741	OHIP: 741
	Syndactyly	Q70	755.1	OHIP: 755
Musculoskeletal disorders	Acromegaly and gigantism	E22.0	253	
	Ankylosing spondylitis	M45, M46	720	OHIP: 720
	Chronic osteomyelitis	M86.3-M86.6	730.1	
	Disc disorders	M50.0, M50.2-M50.9, M51.0, M51.2-M51.9	722	
	Internal derangement of the knee	M22.4, M23.2-M23.5, M23.8, M23.9	717	
	Osteoarthritis	M15-M19	715	OHIP: 715
	Osteochondropathies	M42, M91, M92, M93	732	OHIP: 732
	Osteonecrosis	M87	733.4	
	Osteoporosis with history of pathological fracture	M80	733.1	
	Polymyalgia rheumatica	M35.3	725	OHIP: 725
	Rheumatoid arthritis	M05, M06	714	OHIP: 714
	Spondylosis	M47	721	OHIP: 721

EXHIBITS

EXHIBIT A.1
DIAGNOSTIC CODES USED TO IDENTIFY PHYSICAL DISABILITIES IN HEALTH ADMINISTRATIVE DATA

Disability subtype	Condition	ICD-10 codes	ICD-9 codes	Other codes
Neurological disorders	Cerebral palsy	G80	343	OHIP: 343
	Disorders of autonomic nervous system (e.g., idiopathic peripheral autonomic neuropathy)	G90	337	
	Epilepsy	G40	345.0-345.1, 345.4-345.9	OHIP: 345
	Hemiplegia	G81	342	
	Hereditary and idiopathic neuropathy	G60	356	OHIP: 356
	Hereditary ataxia and other specified degenerative disorders of the nervous system classified elsewhere (e.g., Huntington's disease)	G11, G32.8	334	
	Mononeuropathies of the lower limb	G57, G58	355	
	Multiple sclerosis	G35	340	OHIP: 340
	Muscular dystrophy	G71, G72	359	OHIP: 359
	Myasthenia gravis	G70	358	OHIP: 358
	Nerve root and plexus disorders	G54, G55	353	
	Other demyelinating diseases of central nervous system (e.g., diffuse sclerosis)	G36, G37	341	
	Other disorders of spinal cord (e.g., syringomyelia)	G95	336	
	Other extrapyramidal and movement disorders (e.g., essential tremor)	G10, G23, G24.1-G24.9, G25	333	
	Other paralytic syndromes (e.g., paraplegia)	G82, G83	344	
	Other polyneuropathies (e.g., Guillain-Barre syndrome)	G61, G62, G63	357	
	Other specified degenerative diseases of the nervous system (e.g., cerebral ataxia)	G31.8	331.8	
	Parkinson's disease	G20, G21	332.0-332.1	OHIP: 332
	Sequelae of cardiovascular disease	I69	438	
	Sequelae of poliomyelitis	B91	138	
	Spinal muscular atrophy and related syndromes (e.g., ALS)	G12	335.1, 335.2, 335.8, 335.9	

EXHIBITS

EXHIBIT A.1
DIAGNOSTIC CODES USED TO IDENTIFY PHYSICAL DISABILITIES IN HEALTH ADMINISTRATIVE DATA

Disability subtype	Condition	ICD-10 codes	ICD-9 codes	Other codes
Permanent injuries	Brain injury	S02.0, S02.1, S02.3, S02.7-S02.9, S06.1-S06.9, S07, T02.0, T90.5	800.1, 800.3, 801.1, 801.3, 802.6, 802.7, 803.1, 803.3, 804.1, 804.3, 850, 851-854, 907.0, 907.1	
	Crushing injury of the lower limb	S77, S87, S97.0, T04.1, T04.3-T04.8	928.0-928.2, 928.8	
	Dependence on a wheelchair	Z99.3	V46.3	
	Dependence on other enabling machines and devices	Z99.8	V46.8	
	Fracture of the lower back or pelvis	S32.4-S32.8, T91.2	808	OHIP: 808
	Fracture of the vertebral column with spinal cord injury	S14.0, S14.1, S24.0, S24.1, S34.0, S34.1, S34.3, T06.0, T06.1, T91.3	806, 907.2, 952	OHIP: 806
	Other acquired deformities of limbs	M21.8	736.8	
	Traumatic amputation of the lower limb	S78, S88, S98.0, S98.3, T05, Z89.4-Z89.8	896, 897, V49.7	
	Traumatic amputation of the upper limb	S48, S58, S68.3, S68.4, Z89.1-Z89.3	887, V49.6	

EXHIBITS

EXHIBIT A.2

DIAGNOSTIC CODES USED TO IDENTIFY SENSORY DISABILITIES IN HEALTH ADMINISTRATIVE DATA

Disability subtype	Condition	ICD-10 codes	ICD-9 codes	Other codes
Hearing impairments	Conductive and sensorineural hearing loss	H90, H91.3, H91.8, H91.9	389	389
	Congenital malformations of ear causing impairment of hearing	Q16.0, Q16.1, Q16.3-Q16.9	744	
Vision impairments	Blindness and low vision	H54	369	369
	Cataracts	H25, H26	366	366
	Chorioretinal inflammation	H30, H31	363	
	Congenital malformations of the eye	Q11.1, Q11.2, Q13.1, Q13.3, Q13.8, Q15.0	743.0-743.2, 743.4	
	Disorders of globe (e.g., hypotony of eye)	H44	360	
	Disorders of the iris and ciliary body (e.g., chronic iridocyclitis)	H20.1	364.1	
	Disorders of visual cortex	H47.6	377.7	
	Glaucoma	H40, H42	365	OHIP: 365
	Nystagmus and other irregular eye movements	H55	379.5	
	Other retinal disorders (e.g., other proliferative retinopathy)	E10.31-E10.35, E11.31-E11.35, H34-H36	362	OHIP: 362

EXHIBITS

EXHIBIT A.3
DIAGNOSTIC CODES USED TO IDENTIFY DEVELOPMENTAL DISABILITIES IN HEALTH ADMINISTRATIVE DATA

Disability subtype	Condition	ICD-10 codes	ICD-9 codes	Other codes
Autism spectrum disorder	Autism spectrum disorder	F84.0, F84.1, F84.3-F84.9	299	OHIP: 299; OMHRS: Q2a, Q2b or Q2c (i.e., Axis I) in 299, 299.00, 299.1, 299.10, 299.8, 299.809 (and retired fields)
Other developmental disability	Fetal alcohol spectrum disorder	Q86.0	760.71, 760.77 only if 5 digits exist	
	Intellectual disability	F70-F73, F78, F79	317-319	OHIP: 319; OMHRS: Q2d (i.e., Axis II) in 317, 318, 318.0, 318.1, 318.2, 319 (and retired fields)
	Intellectual disability resulting from chromosomal anomalies	Q90, Q91, Q92.0-Q92.5, Q92.7-Q92.9, Q93, Q97.1, Q99.2, Q99.8	758.0-758.3, 758.5, 758.8 (not 758.81, only if 5 digits exist), 758.9	OMHRS: I11h–I11m = any diagnosis of Qxxx as listed in ICD-10 column
	Other intellectual disabilities (e.g., tuberous sclerosis)	Q85.1, Q86.1, Q87.1, Q87.23, Q87.31, Q87.8	759.5, and the following only if 6 digits exist: 759.821 (not 759.82), 759.827, 759.828, 759.83, 759.874, 759.875, 759.89	OMHRS: I11h–I11m = any diagnosis of Qxxx as listed in ICD-10 column; Q3 = 1

INDICATORS

The final step in creating the Disability and Pregnancy cohort was identifying preconception, pregnancy, labour and birth, and postpartum and newborn health outcomes. For preconception outcomes, we captured social determinants of health, physical health, mental health, medication use and interpersonal violence in all females of reproductive age in 2019/20. For the other outcomes, for births between 2010/11 and 2019/20, we looked at all outpatient visits, emergency department visits and hospital admissions in pregnancy to capture pregnancy outcomes; the birth hospitalization to capture labour and birth outcomes; outpatient visits, emergency department visits and hospital admissions within 365 days of childbirth to capture postpartum outcomes; and hospital admissions within 28 days of birth to capture newborn outcomes.

PRECONCEPTION HEALTH AND PREGNANCY RATES INDICATORS

Social determinants of health

Definition: The proportion of 15 to 49-year-old females without a hysterectomy in Ontario who lived in a neighbourhood in the lowest income quintile, in a neighbourhood in the highest material deprivation quintile or in a neighbourhood in the highest residential instability income quintile.

Numerator: Females living in a neighbourhood in the lowest income quintile, living in a neighbourhood in the highest material deprivation quintile or in a neighbourhood in the highest residential instability quintile.

Denominator: 15 to 49-year-old females without a hysterectomy in Ontario.

Data sources: Ontario Marginalization Index (ONMARG), Registered Persons Database (RPDB), Statistics Canada Census data.

Measurement time frame: October 1, 2019.

Notes:

1. Definitions for the social determinants of health assessed in this Report:
    a. Neighbourhood income quintile: measures the median dissemination area level household income.
    b. Material deprivation: measures access to and attainment of basic material needs, including proportion of the population aged 20 years and older without a high school diploma, proportion of families who are lone parent families, proportion of income from government transfer payments, proportion of the population aged 15 years and older who are unemployed, proportion of the population considered low income and proportion of households living in dwellings in need of major repair.
    c. Residential instability: measure the types and density of residential accommodations, and certain family structure characteristics, including proportion of the population living alone, proportion of the population who are not youth aged 5–15 years, average number of persons per dwelling, proportion of dwellings that are apartment buildings, proportion of the population who are single / divorced / widowed, proportion of dwellings that are not owned and proportion of the population who moved during the last five years.

INDICATORS

PRECONCEPTION HEALTH AND PREGNANCY RATES INDICATORS

Physical health

Definition: The proportion of 15 to 49-year-old females without a hysterectomy in Ontario who had a diagnosis of diabetes mellitus, chronic hypertension or asthma.

Numerator: Females diagnosed with diabetes mellitus, chronic hypertension or asthma.

Denominator: 15 to 49-year-old females without a hysterectomy in Ontario.

Data sources: Ontario Diabetes Database (ODD), Ontario Hypertension Dataset (HYPER) and Ontario Asthma Dataset (ASTHMA).

Measurement time frame: October 1, 2017 to October 1, 2019.

Notes:

1. Definitions for the physical health conditions assessed in this Report:
    a. Diabetes mellitus: two OHIP diagnostic codes (250) or one OHIP fee code (Q040, K029, K030, K045, K046) or one CIHI-DAD admission (ICD-10: E10, E11, E13, E14).
    b. Chronic hypertension: one CIHI-DAD admission (ICD-10: I10, I11, I12, I13, I15) or one OHIP claim (401, 402, 403, 404, 405) followed by a second OHIP claim or a CIHI-DAD admission within two years.
    c. Asthma: two OHIP diagnostic codes (493) or one CIHI-DAD admission (ICD-10: J45, J46).

INDICATORS

PRECONCEPTION HEALTH AND PREGNANCY RATES INDICATORS

Mental health

Definition: The proportion of 15 to 49-year-old females without a hysterectomy in Ontario who had a diagnosis of a mood or anxiety disorder, psychotic disorder, substance use disorder, other mental illness or self-harm.

Numerator: Females diagnosed with a mood or anxiety disorder, psychotic disorder, substance use disorder, other mental illness or self-harm.

Denominator: 15 to 49-year-old females without a hysterectomy in Ontario.

Data sources: Canadian Institute for Health Information Discharge Abstract Database (CIHI-DAD); National Ambulatory Care Reporting System (NACRS); Ontario Health Insurance Plan (OHIP) database; Ontario Mental Health Reporting System (OMHRS).

Measurement time frame: October 1, 2017 to October 1, 2019.

Notes:

1. Definitions for the mental health conditions assessed in this Report:
    a. Mood or anxiety disorder: two OHIP claims (with a general practitioner/ family physician [SPEC=00] with (a) a general service code (A001, A003-A008, A888, A901, A905) for diagnostic codes 300, 309, 311 or (b) a mental health service code (K005, K007, K623) for diagnostic codes 300, 309, 311 OR with a psychiatrist [SPEC=19] for diagnostic codes 300, 309, 311) or one CIHI-DAD admission or NACRS visit (ICD-10: F30-F34, F38-F43, F48.8, F48.9, F53.0) or one OMHRS admission (DSM-IV: 296.x, 300, 300.0x, 300.2x, 300.3x, 300.4x, 308.3x, 309.0x, 309.24, 309.28, 309.3x, 309.4x, 309.8x, 309.9x, 301.13; PROVDX1: 6, 7, 15).
    b. Psychotic disorder: two OHIP claims (with a general practitioner/ family physician [SPEC=00] with (a) a general service code [A001, A003-A008, A888, A901, A905] for diagnostic codes 295, 296, 297, 298 or (b) a mental health service code [K005, K007, K623] for diagnostic codes 295, 296, 297, 298 OR with a psychiatrist [SPEC=19] for diagnostic codes 295, 296, 297, 298) or one CIHI-DAD admission or NACRS visit (ICD-10: F20 [excluding F20.4], F22-F25, F28-F29, F53.1) or one OMHRS admission (DSM-IV: 295.x, 297.x, 298.x; PROVDX1: 5).
    c. Substance use disorder: two OHIP claims (with a general practitioner/ family physician [SPEC=00] with (a) a general service code [A001, A003-A008, A888, A901, A905] for diagnostic codes 303, 304 or (b) a mental health service code [K005, K007, K623] for diagnostic codes 303, 304 OR with a psychiatrist [SPEC=19] for diagnostic codes 303, 304) or one CIHI-DAD admission or NACRS visit (ICD-10: F10-F19, F55) or one OMHRS admission (DSM-IV: 291.x [excluding 291.82], 292.x [excluding 292.85], 303.x, 304.x, 305.x; PROVDX: 4).
    d. Other mental disorder: two OHIP claims (with a general practitioner/ family physician [SPEC=00] with (a) a general service code [A001, A003-A008, A888, A901, A905] for diagnostic codes 301, 302, 306 or (b) a mental health service code [K005, K007, K623] for diagnostic codes 301, 302, 306 OR with a psychiatrist [SPEC=19] for diagnostic codes 301, 302, 306) or one CIHI-DAD admission or NACRS visit (ICD-10: F21, F60-F62, F68, F69) or one OMHRS admission (DSM-IV: 300.16, 300.19, 301.x [all 301 codes excluding 301.1x]; PROVDX: 1, 16).
    e. Self-harm: one NACRS visit (ICD-10: X60-X84, Y10-Y19, Y28).Indicators

INDICATORS

PRECONCEPTION HEALTH AND PREGNANCY RATES INDICATORS

Medication use

Definition: The proportion of 15 to 49-year-old females without a hysterectomy receiving Ontario Drug Benefits who used a potentially teratogenic medication.

Numerator: Females using a potentially teratogenic medication.

Denominator: 15 to 49-year-old females without a hysterectomy in Ontario who were receiving Ontario Drug Benefits.

Data sources: Ontario Drug Benefits (ODB) database.

Measurement time frame: October 1, 2017 to October 1, 2019.

Notes:

1. Potentially teratogenic medications included medications defined by the US Food and Drug Administration, Australian Drug Evaluation Committee and/or Swedish Catalogue of Approved Drugs as teratogenic, and included: anti-infective and anti-parasitic agents, agents acting on the renin angiotensin system, anti-thrombotic agents, statins, dermatologicals, pituitary / hypothalamic and sex hormones, anti-neoplastic agents, immunomodulating agents, anti-epileptic agents, psycholeptic and psychoanaleptic agents and other miscellaneous agents. Refer to Zomerdijk et al.[5] for details.

Interpersonal violence

Definition: The proportion of 15 to 49-year-old females without a hysterectomy in Ontario who had an emergency department visit for interpersonal violence.

Numerator: Females with a history of emergency department visits for interpersonal violence.

Denominator: 15 to 49-year-old females without a hysterectomy in Ontario.

Data sources: National Ambulatory Care Reporting System (NACRS)

Measurement time frame: Any time prior to October 1, 2019.

Notes:

1. In this chapter, history of interpersonal violence is defined by one NACRS visit (ICD-9: 960-969 accompanied by dxtype=9; ICD-10: X85 to Y09).

Pregnancy rate

Definition: The proportion of 15 to 49-year-old females without a hysterectomy in Ontario who had a livebirth, stillbirth, induced abortion or miscarriage.

Numerator: The number of females with a livebirth, stillbirth, induced abortion or miscarriage.

Denominator: The number of females aged 15 to 49 years in Ontario.

Data sources: Canadian Institute for Health Information Discharge Abstract Database (CIHI-DAD), including the CIHI-DAD-derived MOMBABY dataset; National Ambulatory Care Reporting System (NACRS); Ontario Health Insurance Plan (OHIP) database.

Measurement time frame: April 1, 2019 to March 31, 2020.

Notes:

1. Definitions of livebirth, stillbirth, induced abortion and miscarriage used in this report:
   a. Livebirth at 20 weeks gestation or greater: m_stillbirth=F in MOMBABY
   b. Stillbirth at 20 weeks gestation or greater: m_stillbirth=T in MOMBABY
   c. Induced abortion at less than 20 weeks gestation: one OHIP claim ([635, 895] and S752 OR [635, 895] and [S785, A920, P001]) or CIHI-DAD admission or NACRS visit ([ICD-10: O04, O08] and [CCI: 5CA20FK, 5CA24, 5CA88, or FCA89] [INATSTAT not equal to A])
   d. Miscarriage at less than 20 weeks gestation: one OHIP claim ([632, 633, 634, or 640] and [A920 or P001] OR A922 OR [632, 633, 634, or 640]) and ([S752 or S785] OR [S756, S768, S770, or S784]) or CIHI-DAD admission or NACRS visit (ICD-10: O00, O02.1, O03)

INDICATORS

PRENATAL INDICATORS

Prenatal care access

Definition: The proportion of 15 to 49-year-old females with a singleton livebirth or stillbirth in Ontario who had their first prenatal care visit with an obstetrician or general practitioner/family physician by 12 weeks gestation and who had at least 11 prenatal care visits during pregnancy.[6]

Numerator: Females with their first prenatal care visit with an obstetrician or general practitioner/family physician by 12 weeks gestation and who had at least 11 prenatal care visits during pregnancy.

Denominator: 15 to 49-year-old females with a singleton livebirth or stillbirth in Ontario.

Data sources: ICES Physician Database (IPDB); Ontario Health Insurance Plan (OHIP) database.

Measurement time frame: April 1, 2010 and March 31, 2020.

Notes:

1. In this report, prenatal care visits are those coded as A, K, P003, P004, P005 with a GP/FP (main specialty in IPDB = "GP/FP") or obstetrician (main specialty in IPDB = "OBSTETRICS AND GYNECOLOGY").

Hospital care during pregnancy

Definition: The proportion of 15 to 49-year-old females with a singleton livebirth or stillbirth in Ontario who had an emergency department visit or a hospital admission for an obstetrical, other medical or psychiatric reason in pregnancy.

Numerator: Females who had an emergency department visit or a hospital admission for an obstetrical, other medical or psychiatric reason in pregnancy.

Denominator: 15 to 49-year-old females with a singleton obstetrical delivery in Ontario.

Data sources: Canadian Institute for Health Information Discharge Abstract Database (CIHI-DAD); National Ambulatory Care Reporting System (NACRS); Ontario Mental Health Reporting System (OMHRS).

Measurement time frame: April 1, 2010 to March 31, 2020.

Notes:

1. In this chapter, hospital care in pregnancy is defined as:
    a. Emergency department visits: Any emergency department visit between conception and delivery, excluding those who left the emergency department without being seen, but including transferred emergency department visits. These were classified as obstetrical (any "O" code), psychiatric (any "F" code) or other medical (all other ICD-10 codes) based on the diagnosis used to describe the primary reason for the encounter.
    b. Hospital admissions: Any hospital admission between conception and delivery, not including the birth hospital stay. These were classified as obstetrical (any "O" code), psychiatric (any "F" code) or other medical (all other ICD-10 codes) based on the diagnosis used to describe the primary reason for the encounter.

Prenatal physical health

Definition: The proportion of 15 to 49-year-old females with a singleton livebirth or stillbirth in Ontario with a serious physical health complication, including death, between conception and delivery.

Numerator: Females with a serious physical health complication, including death, between conception and delivery.

Denominator: 15 to 49-year-old females with a singleton livebirth or stillbirth in Ontario.

Data sources: Canadian Institute for Health Information Discharge Abstract Database (CIHI-DAD); National Ambulatory Care Reporting System (NACRS).

Measurement time frame: April 1, 2010 to March 31, 2020.

Notes:

1. In this chapter, serious physical health complications are defined by the presence of the diagnoses and interventions listed in Exhibit A.4.[7]

EXHIBITS

EXHIBIT A.4

DIAGNOSTIC CODES USED TO IDENTIFY SERIOUS PHYSICAL HEALTH COMPLICATIONS

Outcome	Codes or definition
Acute abdomen	ICD-10: K35, K37, K65, N73.3, N73.5
Acute fatty liver with red blood cell (RBC) or plasma transfusion	ICD-10: O26.6 + (RBCTRNSF=‘Y’ or PLSTRNSF=’Y’)
Acute psychosis	ICD-10: F53.1, F23
Acute renal failure	ICD-10: O90.4, N17, N19, N99.0
Adult respiratory distress syndrome	ICD-10: J80
Antepartum hemorrhage with coagulation defect	ICD-10: O46.0
Assisted ventilation through endotracheal tube	CCI: 1.GZ.31.CA-ND
Assisted ventilation through tracheostomy	CCI: 1.GZ.31.CR-ND
Cardiac conditions	ICD-10: O74.2, O75.4, O89.1, O90.3, I21, I22, I42, I43, I46, I49.0, I50, J81; CCI: 1.HZ.09, 1.HZ.30
Cerebral edema or coma	ICD-10: G93.6, R40.2
Cerebral venous thrombosis in pregnancy, or in the puerperium	ICD-10: O22.5 or O87.3
Cerebrovascular diseases: subarachnoid and intracranial hemorrhage, cerebral infarction, stroke	ICD-10: I60-I64
Complications of obstetric surgery and procedures	ICD-10: O75.4
Curettage with RBC transfusion	(5.PC.91.GA, 5.PC.91.GC or 5.PC.91.GD) + RBCTRNSF=‘Y’
Dialysis	CCI: 1.PZ.21^^
Disseminated intravascular coagulation	ICD-10: D65
Eclampsia	ICD-10: O15
Evacuation of incisional hematoma with RBC transfusion	5.PC.73.JS + RBCTRNSF=‘Y’
Hepatic failure	ICD-10: K71-K72
Hysterectomy	CCI: 5.MD.60.RC, 5.MD.60.RD, 5.MD.60.KE, 5.MD.60.CB, 1.RM.89.LA (exclude if 1.PL.74, 1.RS.74 or 1.RS.80 code also present), 1.RM.87.LA-GX
Intrapartum hemorrhage with coagulation defect	ICD-10: O67.0
Intrapartum hemorrhage with RBC transfusion	ICD-10: O67 + blood transfusion
Maternal ICU admission	ftspcu in (‘10’, ’20’, ’25’, ’30’, ’35’, ’40’, ’45’, ’60’, ‘80’)
Maternal mortality	n/a
Obstetric embolism	ICD-10: O88
Obstetric shock	ICD-10: O75.1, R57, T80.5, T88.6
Placenta previa with hemorrhage with RBC transfusion	ICD-10: O44.1 + RBCTRNSF=‘Y’
Placental abruption with coagulation defect	ICD-10: O45.0
Postpartum hemorrhage with RBC transfusion, procedures to the uterus or hysterectomy	ICD-10: O72 + (RBCTRNSF=‘Y’ or [CCI: 1.RM.13^^ or 1.KT.51 or 5.PC.91.LA or 5.PC.91.HV + (RBCTRNSF=1)] or [CCI: 5.MD.60.RC, 5.MD.60.RD, 5.MD.60.KE, 5.MD.60.CB, 1.RM.89.LA] or 1.RM.87.LA-GX). Note: 1.RM.89.LA is included only if codes 1.PL.74, 1.RS.74 or 1.RS.80 are NOT also present
Procedures to the uterus/pelvic vessels with RBC transfusion	(1.RM.13^^ or 1.KT.51 or 5.PC.91.LA) + blood transfusion

EXHIBITS

EXHIBIT A.4
DIAGNOSTIC CODES USED TO IDENTIFY SERIOUS PHYSICAL HEALTH COMPLICATIONS

Outcome	Codes or definition
Puerperal sepsis	ICD-10: O85
Pulmonary, cardiac, and CNS complications of anaesthesia during pregnancy, the puerperium, or labour and delivery	ICD-10: O29.0, O29.1, O29.2, O74.0, O74.1, O74.2, O74.3, O89.0, O89.1, O89.2
Reclosure of caesarean wound with RBC transfusion	(5.PC.80.JM or 5.PC.80.JH) + RBCTRNSF=‘Y’
Repair of bladder, urethra, or intestine	CCI: 5.PC.80.JR, 1.NK.80^^, 1.NM.80^^
Rupture of the uterus with RBC transfusion, procedures to the uterus or hysterectomy	(ICD-10: O71.0 or O71.1) + (RBCTRNSF=‘Y’ or [CCI: 1.RM.13^^ or 1.KT.51 or 5.PC.91.LAor 5.PC.91.HV] or [CCI: 5.MD.60.RC, 5.MD.60.RD, 5.MD.60.KE, 5.MD.60.CB, 1.RM.89.LA, 1.RM.87.LA-GX]). Note: 1.RM.89.LA is included only if codes 1.PL.74, 1.RS.74 or 1.RS.80 are NOT also present
Septicemia during labour	ICD-10: O75.3
Severe preeclampsia and HELLP syndrome	ICD-10: O14.1, O14.2
Sickle cell anemia with crisis	ICD-10: D57.0
Status asthmaticus	ICD-10: J45.01, J45.11, J45.81, J45.91
Status epilepticus	ICD-10: G41
Surgical or manual correction of inverted uterus for vaginal births only	CCI: 5.PC.91.HQ or 5.PC.91.HP, restricted to vaginal births (i.e., absence of caesarean code 5.MD.60)

INDICATORS

PRENATAL INDICATORS

Prenatal mental health

Definition: The proportion of 15 to 49-year-old females with a singleton livebirth or stillbirth in Ontario who had a diagnosis of a mood or anxiety disorder, psychotic disorder, substance use disorder, other mental illness or self-harm between conception and delivery.

Numerator: Females diagnosed with a mood or anxiety disorder, psychotic disorder, substance use disorder, other mental illness or self-harm between conception and delivery.

Denominator: 15 to 49-year-old females with a singleton livebirth or stillbirth in Ontario.

Data sources: Canadian Institute for Health Information Discharge Abstract Database (CIHI-DAD); National Ambulatory Care Reporting System (NACRS); Ontario Health Insurance Plan (OHIP) database; Ontario Mental Health Reporting System (OMHRS).

Measurement time frame: April 1, 2010 to March 31, 2020.

Notes:

1. Definitions for the mental health conditions assessed in this Report:
    a. Mood or anxiety disorder: one OHIP claim (with a general practitioner/family physician [SPEC=00] with (a) a general service code [A001, A003-A008, A888, A901, A905] for diagnostic codes 300, 309, 311 or (b) a mental health service code [K005, K007, K623] for diagnostic codes 300, 309, 311 OR with a psychiatrist [SPEC=19] for diagnostic codes 300, 309, 311) or one CIHI-DAD admission or NACRS visit (ICD-10: F30-F34, F38-F43, F48.8, F48.9, F53.0) or one OMHRS admission (DSM-IV: 296.x, 300, 300.0x, 300.2x, 300.3x, 300.4x, 308.3x, 309.0x, 309.24, 309.28, 309.3x, 309.4x, 309.8x, 309.9x, 301.13; PROVDX1: 6, 7, 15).
    b. Psychotic disorder: one OHIP claim (with a general practitioner/family physician [SPEC=00] with (a) a general service code [A001, A003-A008, A888, A901, A905] for diagnostic codes 295, 296, 297, 298 or (b) a mental health service code [K005, K007, K623] for diagnostic codes 295, 296, 297, 298 OR with a psychiatrist [SPEC=19] for diagnostic codes 295, 296, 297, 298) or one CIHI-DAD admission or NACRS visit (ICD-10: F20 [excluding F20.4], F22-F25, F28-F29, F53.1) or one OMHRS admission (DSM-IV: 295.x, 297.x, 298.x; PROVDX1: 5).
    c. Substance use disorder: one OHIP claim (with a general practitioner/family physician [SPEC=00] with (a) a general service code [A001, A003-A008, A888, A901, A905] for diagnostic codes 303, 304 or (b) a mental health service code [K005, K007, K623] for diagnostic codes 303, 304 OR with a psychiatrist [SPEC=19] for diagnostic codes 303, 304) or one CIHI-DAD admission or NACRS visit (ICD-10: F10-F19, F55) or one OMHRS admission (DSM-IV: 291.x [excluding 291.82], 292.x [excluding 292.85], 303.x, 304.x, 305.x; PROVDX: 4).
    d. Other mental disorder: one OHIP claim (with a general practitioner/family physician [SPEC=00] with (a) a general service code [A001, A003-A008, A888, A901, A905] for diagnostic codes 301, 302, 306 or (b) a mental health service code [K005, K007, K623] for diagnostic codes 301, 302, 306 OR with a psychiatrist [SPEC=19] for diagnostic codes 301, 302, 306) or one CIHI-DAD admission or NACRS visit (ICD-10: F21, F60-F62, F68, F69) or one OMHRS admission (DSM-IV: 300.16, 300.19, 301.x [all 301 codes excluding 301.1x]; PROVDX: 1, 16).
    e. Self-harm: one NACRS visit (ICD-10: X60-X84, Y10-Y19, Y28).

INDICATORS

PRENATAL INDICATORS

Prenatal interpersonal violence

Definition: The proportion of 15 to 49-year-old females with a singleton livebirth or stillbirth in Ontario who had an emergency department visit for interpersonal violence between conception and delivery.

Numerator: Females who had an emergency department visit for interpersonal violence between conception and delivery.

Denominator: 15 to 49-year-old females with a singleton livebirth or stillbirth in Ontario.

Data sources: National Ambulatory Care Reporting System (NACRS).

Measurement time frame: April 1, 2010 to March 31, 2020.

Notes:

1. In this chapter, interpersonal violence in pregnancy, including assault and maltreatment, is defined by one NACRS visit (ICD-10: T73, T74, X85 to Y09, Y87.1, Z04.4, Z04.50, Z04.51, Z04.58, Z61.4-Z61.6, Z62.9, Z70.2, Z70.3).[8]

LABOUR AND BIRTH INDICATORS

Labour and delivery interventions

Definition: The proportion of 15 to 49-year-old females with a singleton livebirth or stillbirth in Ontario who had a labour induction, assisted vaginal delivery (i.e., forceps or vacuum extraction), or Caesarean delivery.

Numerator: Females who had a labour induction, assisted vaginal delivery or Caesarean delivery.

Denominator: 15 to 49-year-old females with a singleton livebirth or stillbirth in Ontario.

Data sources: Canadian Institute for Health Information Discharge Abstract Database (CIHI-DAD) MOMBABY dataset.

Measurement time frame: April 1, 2010 to March 31, 2020.

Notes:

1. Definitions for the labour and delivery interventions assessed in this Report:
    a. Labour induction: CCI: 5.AC.30
    b. Assisted vaginal delivery: CCI: 5.MD.53, 54,55, 5MD56PC/PF/PJ
    c. Caesarean delivery: CCI: 5.MD.60

INDICATORS

LABOUR AND BIRTH INDICATORS

Birth outcomes

Definition: The proportion of liveborn infants of 15 to 49-year-old females in Ontario who were born preterm and small for gestational age.

Numerator: Liveborn infants born at less than 37 weeks and less than 34 weeks and small for gestational age less than the 10th percentile and less than the 3rd percentile.

Denominator: Liveborn infants of 15 to 49-year-old females in Ontario.

Data sources: Canadian Institute for Health Information Discharge Abstract Database (CIHI-DAD) MOMBABY dataset.

Measurement time frame: April 1, 2010 to March 31, 2020.

Notes:

1. Definitions for birth outcomes assessed in this Report:
    a. Preterm birth: birth at less than 37 weeks gestational age and less than 34 weeks gestational age according to the MOMBABY b_gestweeks_del variable.
    b. Small for gestational age: birth weight less than the 10th percentile and less than the 3rd percentile for gestational age, according to population norms.[9]

Length of stay

Definition: The proportion of 15 to 49-year-old females with a singleton livebirth in Ontario with a hospital stay of more than two days (vaginal births) or more than three days (Caesarean births), and the proportion of their term newborns with a hospital stay of more than two days.[10]

Numerator: Females with a hospital stay of more than two days (vaginal births) or three days (Caesarean births), and term newborns with a hospital stay of more than two days.

Denominator: 15 to 49-year-old females with a singleton livebirth in Ontario, and their newborns delivered at 37 weeks gestation or greater.

Data sources: Canadian Institute for Health Information Discharge Abstract Database (CIHI-DAD) MOMBABY dataset.

Measurement time frame: April 1, 2010 to March 31, 2020.

Stratification variables: Delivery mode for females (vaginal and Caesarean) and gestational age (births at 37 weeks or greater) for newborns.

Notes:

1. Definitions for length of stay assessed in this Report:
    a. Females: Days from admission to discharge for the birth hospital stay.
    b. Term newborns: Days from birth to discharge for the birth hospital stay.

INDICATORS

LABOUR AND BIRTH INDICATORS

Breastfeeding initiation

Definition: The proportion of 15 to 49-year-old females with a singleton livebirth in Ontario who had any breastfeeding and exclusive breastfeeding before discharge from the birth hospital stay.

Numerator: Females who had any breastfeeding and exclusive breastfeeding before discharge from the birth hospital stay.

Denominator: 15 to 49-year-old females with a singleton livebirth in Ontario.

Data sources: Better Outcomes Registry & Network (BORN) Information System.

Measurement time frame: April 1, 2012 and March 31, 2018.

Notes:

1. Definitions for breastfeeding initiation assessed in this Report:
    a. Any breastfeeding before discharge from the birth hospital stay, using NEWBORN_FEEDING_AT_DISCHARGE_ID, FEEDING_AT_HOSPITAL_OR_MPG_ID and BFI_PPC_NICU_NEWBORN_FEED_TYPEID variables.[11]
    b. Exclusive breastfeeding before discharge from the birth hospital stay, using NEWBORN_FEEDING_AT_DISCHARGE_ID, FEEDING_AT_HOSPITAL_OR_MPG_ID and BFI_PPC_NICU_NEWBORN_FEED_TYPEID variables.[11]

Breastfeeding support

Definition: The proportions of 15 to 49-year-old females with a singleton livebirth in Ontario who had skin-to-skin contact within two hours of birth and provision of assistance with breastfeeding within six hours of birth after initial feeding.

Numerator: Females who had skin-to-skin contact within two hours of birth and provision of assistance with breastfeeding within six hours of birth after initial feeding.

Denominator: 15 to 49-year-old females with a singleton livebirth in Ontario.

Data sources: Better Outcomes Registry & Network (BORN) Information System.

Measurement time frame: April 1, 2012 and March 31, 2018.

Notes:

1. Definitions for breastfeeding support assessed in this Report:
    a. Skin-to-skin contact with the birthing parent within two hours of birth using FEEDING_INITIATION_ID variable.[11]
    b. Provision of assistance with breastfeeding within six hours of birth after initial feeding using POSTPART_BREASTFEED_SUPPORT_ID variable.[11]

INDICATORS

POSTPARTUM AND NEWBORN INDICATORS

Postpartum care access

Definition: The proportion of 15 to 49-year-old females with a singleton livebirth or stillbirth in Ontario who had a routine six-week postpartum visit with an obstetrician or general practitioner/family physician.

Numerator: Females who had a postpartum visit with an obstetrician or general practitioner/family physician by eight weeks after childbirth.

Denominator: 15 to 49-year-old females with a singleton livebirth or stillbirth in Ontario.

Data sources: ICES Physician Database (IPDB); Ontario Health Insurance Plan (OHIP) database.

Measurement time frame: April 1, 2010 to March 31, 2020.

Notes:

1. In this Report, postpartum care visits are those coded as A, K, P003, P004, P005 with a GP/FP (main specialty in IPDB = “GP/FP”) or obstetrician (main specialty in IPDB = “OBSTETRICS AND GYNECOLOGY”) by 8 weeks (as a buffer for scheduling of late appointments).

Hospital care in the postpartum period

Definition: The proportion of 15 to 49-year-old females with a singleton livebirth or stillbirth in Ontario who had an emergency department visit or hospital admission for obstetrical, other medical or psychiatric reasons between delivery hospital stay discharge and 365 days thereafter.

Numerator: Females with an emergency department visit or hospital admission for obstetrical, other medical or psychiatric reasons between delivery hospital stay discharge and 365 days thereafter.

Denominator: 15 to 49-year-old females with a singleton livebirth or stillbirth in Ontario.

Data sources: Canadian Institute for Health Information Discharge Abstract Database (CIHI-DAD); National Ambulatory Care Reporting System (NACRS); Ontario Mental Health Reporting System (OMHRS).

Measurement time frame: April 1, 2010 to March 31, 2020.

Notes:

1. In this chapter, emergency department visits and hospital admissions in the postpartum period are defined as follows:
   a. Emergency department visits: any emergency department visit between delivery and 365 days thereafter, excluding those who left the emergency department without being seen, but including transferred emergency department visits. These were classified as obstetrical (any “O” code), psychiatric (any “F” code) or other medical (all other ICD-10 codes) based on the diagnosis used to describe the primary reason for the encounter.
   b. Hospital admissions: any hospital admission between delivery and 365 days thereafter, not including the birth hospital stay. These were classified as obstetrical (any “O” code), psychiatric (any “F” code) or other medical (all other ICD-10 codes) based on the diagnosis used to describe the primary reason for the encounter.

INDICATORS

POSTPARTUM AND NEWBORN INDICATORS

Postpartum physical health

Definition: The proportion of 15 to 49-year-old females with a singleton livebirth or stillbirth in Ontario with a serious physical health complication, including death, between delivery and 42 days thereafter, and 43–365 days thereafter.

Numerator: Females with a serious physical health complication or who died between delivery and 42 days thereafter, and 43–365 days thereafter.

Denominator: 15 to 49-year-old females with a singleton livebirth or stillbirth in Ontario.

Data sources: Canadian Institute for Health Information Discharge Abstract Database (CIHI-DAD), National Ambulatory Care Reporting System (NACRS).

Measurement time frame: April 1, 2010 to March 31, 2020.

Notes:

1. In this chapter, serious physical health complications are defined by the presence of the diagnoses and interventions listed above in Exhibit A.4.

Postpartum mental health

Definition: The proportion of 15 to 49-year-old females with a singleton livebirth or stillbirth in Ontario who had a diagnosis of a mood or anxiety disorder, psychotic disorder, substance use disorder, other mental illness or self-harm between delivery and 365 days thereafter.

Numerator: Females diagnosed with a mood or anxiety disorder, psychotic disorder, substance use disorder, other mental illness or self-harm between delivery and 365 days thereafter.

Denominator: 15 to 49-year-old females with a singleton livebirth or stillbirth in Ontario.

Data sources: Canadian Institute for Health Information Discharge Abstract Database (CIHI-DAD); National Ambulatory Care Reporting System (NACRS); Ontario Health Insurance Plan (OHIP) database; Ontario Mental Health Reporting System (OMHRS).

Measurement time frame: April 1, 2010 to March 31, 2020.

Notes:

1. Definitions for the mental health conditions assessed in this Report:
    a. Mood or anxiety disorder: one OHIP claim (with a general practitioner/family physician [SPEC=00] with (a) a general service code [A001, A003-A008, A888, A901, A905] for diagnostic codes 300, 309, 311 or (b) a mental health service code [K005, K007, K623] for diagnostic codes 300, 309, 311 OR with a psychiatrist [SPEC=19] for diagnostic codes 300, 309, 311) or one CIHI-DAD admission or NACRS visit (ICD-10: F30-F34, F38-F43, F48.8, F48.9, F53.0) or one OMHRS admission (DSM-IV: 296.x, 300, 300.0x, 300.2x, 300.3x, 300.4x, 308.3x, 309.0x, 309.24, 309.28, 309.3x, 309.4x, 309.8x, 309.9x, 301.13; PROVDX1: 6, 7, 15).
    b. Psychotic disorder: one OHIP claim (with a general practitioner/family physician [SPEC=00] with (a) a general service code [A001, A003-A008, A888, A901, A905] for diagnostic codes 295, 296, 297, 298 or (b) a mental health service code [K005, K007, K623] for diagnostic codes 295, 296, 297, 298 OR with a psychiatrist [SPEC=19] for diagnostic codes 295, 296, 297, 298) or one CIHI-DAD admission or NACRS visit (ICD-10: F20 [excluding F20.4], F22-F25, F28-F29, F53.1) or one OMHRS admission (DSM-IV: 295.x, 297.x, 298.x; PROVDX1: 5).
    c. Substance use disorder: one OHIP claim (with a general practitioner/family physician [SPEC=00] with (a) a general service code [A001, A003-A008, A888, A901, A905] for diagnostic codes 303, 304 or (b) a mental health service code [K005, K007, K623] for diagnostic codes 303, 304 OR with a psychiatrist [SPEC=19] for diagnostic codes 303, 304) or one CIHI-DAD admission or NACRS visit (ICD-10: F10-F19, F55) or one OMHRS admission (DSM-IV: 291.x [excluding 291.82], 292.x [excluding 292.85], 303.x, 304.x, 305.x; PROVDX: 4).
    d. Other mental disorder: one OHIP claim (with a general practitioner/family physician [SPEC=00] with (a) a general service code [A001, A003-A008, A888, A901, A905] for diagnostic codes 301, 302, 306 or (b) a mental health service code [K005, K007, K623] for diagnostic codes 301, 302, 306 OR (2) with a psychiatrist [SPEC=19] for diagnostic codes 301, 302, 306) or one CIHI-DAD admission or NACRS visit (ICD-10: F21, F60-F62, F68, F69) or one OMHRS admission (DSM-IV: 300.16, 300.19, 301.x [all 301 codes excluding 301.1x]; PROVDX: 1, 16).
    e. Self-harm: one NACRS visit (ICD-10: X60-X84, Y10-Y19, Y28).

INDICATORS

POSTPARTUM AND NEWBORN INDICATORS

Postpartum interpersonal violence

Definition: The proportion of 15 to 49-year-old females with a singleton livebirth or stillbirth in Ontario who had an emergency department visit for interpersonal violence between delivery and 365 days thereafter.

Numerator: Females who had an emergency department visit for interpersonal violence between delivery and 365 days thereafter.

Denominator: 15 to 49-year-old females with a singleton livebirth or stillbirth in Ontario.

Data sources: National Ambulatory Care Reporting System (NACRS).

Measurement time frame: April 1, 2010 to March 31, 2020.

Notes:

1. In this chapter, interpersonal violence in the postpartum period, including assault and maltreatment, is defined by one NACRS visit (ICD-10: T73, T74, X85 to Y09, Y87.1, Z04.4, Z04.50, Z04.51, Z04.58, Z61.4-Z61.6, Z62.9, Z70.2, Z70.3).

Neonatal intensive care unit admission

Definition: The proportion of newborns to 15 to 49-year-old females in Ontario who were admitted to a neonatal intensive care unit in the first 28 days of life.

Numerator: Newborns admitted to a neonatal intensive care unit in the first 28 days of life.

Denominator: 15 to 49-year-old females with a singleton livebirth in Ontario.

Data sources: Canadian Institutes for Health Information Discharge Abstract Database (CIHI-DAD).

Measurement time frame: April 1, 2010 to March 31, 2020.

Notes:

1. In this chapter, neonatal intensive care unit admission is defined as SCU = 45, 50, 51, 52, 53.

The Disability and Pregnancy Study Participants: An Overview

In parallel with population-level health administrative data, we interviewed 31 people with disabilities and 31 service-providers and decision-makers about the pregnancy care experiences of people with disabilities.

Convenience sampling was used for recruitment of participants, with purposeful sampling to attain a diverse sample of participants with regard to disability type, race/ethnicity and geography. Participants were recruited via distribution of flyers through electronic mailing lists, newsletters, websites and social media pages of over 100 organizations that serve people with disabilities and/or pregnant and parenting people across Ontario, through the research team's networks, and through the study Advisory Committee that was comprised of women with disabilities, researchers, clinicians, staff from community organizations and provincial policy representatives. Interested individuals contacted the study office and were screened by telephone to determine eligibility.

People with disabilities were eligible if they (a) identified as having a physical, sensory and/or developmental disability, (b) resided in Ontario, (c) were 18 years of age or older, (d) had given birth in the last five years and (e) were able to converse in English or American Sign Language. Service-providers and decision-makers were eligible if they (a) worked in Ontario and (b) were able to converse in English or American Sign Language.

EXHIBITS

EXHIBIT A.5
CHARACTERISTICS OF PARTICIPANTS WITH DISABILITIES

Characteristic	Category	Number with characteristic
Age (years)	18-25	3
	26-34	14
	35-45	14
Gender identity	Cisgender woman	29
	Trans or non-binary	2
Sexual orientation	Asexual	1
	Heterosexual	25
	Lesbian, bisexual, or queer	5
Relationship status	Dating	3
	Married or common-law	22
	Separated or single	8
Highest level of education	High school or less	13
	College	6
	Undergraduate degree	5
	Graduate or professional degree	6
	Missing	1
Self-described racial/ethnic background	African	1
	Arab/Jewish	1
	Black	1
	Chinese	1
	East Indian	1
	Filipino	2
	Guyanese	1
	Hispanic	1
	Indigenous or Métis	2
	Israeli	1
	South American	1
	White/Canadian/European	21
Annual household income (CAD)	$39,999 or less	16
	$40,000-79,999	8
	$80,000 or more	7
Place of residence	Small town (population < 30,000)	7
	Medium-sized town (30,000 to 99,999)	2
	Small city (100,000 to 499,999)	8
	Large city (population ≥ 500,000)	14

EXHIBITS

EXHIBIT A.6
CHARACTERISTICS OF SERVICE-PROVIDERS AND DECISION-MAKERS

Characteristic	Category	Number with characteristic
Professional designation	Medical doctor (e.g., obstetrician-gynecologist, maternal-fetal medicine, family physician)	7
	Registered nurse (e.g., antenatal, public health)	7
	Nurse practitioner / Registered nurse-extended class	2
	Midwife	3
	Social worker	6
	Occupational therapist	2
	Decision-maker (e.g., policy-maker, program director)	13
Years in current position	Less than 3 years	6
	3-5 years	4
	6-10 years	6
	11-20 years	11
	≥ 21 years	3
Sex	Female	27
	Male	3
	Prefer not to answer	1
Disability	Yes	7
	No	23
	Prefer not to answer	1
Location	Very large city (population over 1 million)	22
	Large city (population ≥ 500,000 to < 1 million)	4
	Small city (population 100,000 to 499,999)	3
	Medium/small town (population less than 100,000)	2

INTERVIEWS

Interviews were conducted by two researchers (a postdoctoral fellow and peer researcher who self-identified as having a physical disability) between July 2019 and February 2020. Nineteen interviews were conducted in-person, and the rest by telephone or Zoom. All interviews were audio-recorded. Interview time ranged between 36 and 124 minutes (Mean=73 minutes) for people with disabilities and between 11 and 62 minutes (Mean=34 minutes) for service-providers and decision-makers. Five participants with disabilities requested to have a support person (e.g., parent or caseworker) with them during the interview. Interpreters were employed to assist with communication between researchers and four participants. Before the interviews, all support persons and interpreters signed a confidentiality agreement. Their responses are not included in this Report.

Before each interview, the interviewers reviewed the information letter and consent form to clarify the study's purpose, what participation entailed, the benefits and risks of participation and confidentiality, and to address questions. Interviewers reminded participants that they were not obligated to answer any questions and that they could take breaks. Participants then completed a demographic and pregnancy history questionnaire.

The interviews were semi-structured, following a guide developed in collaboration with the Advisory Committee. Interviews for people with disabilities began with general questions about participants' family or support system and disability, and then followed the chronology of participants' most recent pregnancy care experience. They were asked about pregnancy planning, and care during pregnancy, labour and birth, and the postpartum period, including the types of services and supports they accessed, if they found these to be helpful, and what they would recommend to improve pregnancy care for disabled people.

Interviews with service-providers and decision-makers asked about their disability-related training experiences, the types of pregnancy-related services and supports that are most helpful to people with disabilities, the current strengths and gaps in pregnancy care for people with disabilities, and what they would recommend to improve pregnancy care for people with disabilities.

After the interview, participants with disabilities received a $50 gift card and service-providers and decision-makers received a $25 gift card (e.g., from a grocery store). Participants with disabilities also received a document of resources on mental health and violence against women. Within one week, they were contacted to inquire about their wellbeing and to ask if there was anything they wanted to add. No participants finished the interview early, withdrew or reported difficulties post-interview.

Interviews were transcribed intelligent verbatim (e.g., false starts, filler words, or utterances like 'um' were omitted), and names were replaced with pseudonyms. We used a reflexive thematic analysis approach to identify themes.[12] Throughout analysis, we were reflexive of our knowledge of related research and our lived experiences. Two researchers who conducted the interviews familiarized themselves with the data by reviewing field notes and verifying interview transcripts, and re-reading and discussing several transcripts together with each other and the broader research team. Based on these discussions, two researchers co-developed a list of codes, which served as a coding framework for the dataset. NVivo 12 (QSR International) was used for the documentation and organization of codes. After all transcripts were coded, the coding framework was revised and theme memos were constructed, whereby similar codes were grouped together, with their associated data, into potential themes. Through discussion with the larger study team, the content, structure and names of themes were revised.

RETURN TO PREVIOUS PAGE

References

1. Lin E, Balogh R, Cobigo V, Ouellette-Kuntz H, Wilton AS, Lunsky Y. Using administrative health data to identify individuals with intellectual and developmental disabilities: a comparison of algorithms. *J Intellect Disabil Res* 2013; 57(5):462–77.
2. Horner-Johnson W, Biel FM, Darney BG, Caughey AB. Time trends in births and cesarean deliveries among women with disabilities. *Disabil Health J* 2017; 10(3):376–81.
3. Brown HK, Carty A, Havercamp S, Parish S, Lunsky Y. Algorithms to identify reproductive-aged women with physical and sensory disabilities in administrative health data: a systematic review. *Disabil Health J* 2020; 13(3):100909.
4. Statistics Canada. *Live births and fetal deaths (stillbirths) by place of birth (hospital or non-hospital), Canada, provinces and territories, annual, 2021.* Ottawa: Statistics Canada; 2021. Accessed July 26, 2021. https://www150.statcan.gc.ca/t1/tbl1/en/tv.action?pid=1310042901.
5. Zomerdijk IM, Ruiter R, Houweling LMA, Herings RMC, Straus SMJM, Stricker BH. Dispensing of potentially teratogenic drugs before conception and during pregnancy: a population-based study. *BJOG* 2015; 122(8):1119–29.
6. Alexander GR, Kotelchuck M. Quantifying the adequacy of prenatal care: a comparison of indices. *Public Health Rep.* 1996; 111(5):408–18.
7. Ray JG, Park AL, Dzakpasu S, Dayan N, Deb-Rinker P, Luo W, et al. Prevalence of severe maternal morbidity and factors associated with maternal mortality in Ontario, Canada. *JAMA Netw Open* 2018; 1(7):e184571.
8. Saunders N, Plumptre L, Diong C, Gandhi S, Schull M, Guttmann A, et al. Acute care visits for assault and maltreatment before vs during the COVID-19 pandemic in Ontario, Canada. *JAMA Health Forum* 2021; 2:e211983.
9. Ray JG, Sgro M, Mamdani MM, Glazier RH, Bocking A, Hilliard R, et al. Birth weight curves tailored to maternal world region. *J Obstet Gynaecol Can* 2012; 34:159–71.
10. Lemyre B, Jefferies AL, O'Flaherty P. *Facilitating discharge from hospital of the healthy term infant.* Ottawa: Canadian Paediatric Society; 2018.
11. Taylor CL, Brown HK, Saunders NR, Barker LC, Chen S, Cohen E, et al. Maternal schizophrenia, skin-to-skin contact, and infant feeding initiation. *Schizophr Bull* 2022; 48(1):145–53.
12. Braun V, Clarke V. *Thematic analysis: a practical guide.* United Kingdom: SAGE Publications; 2021.

GET IN TOUCH

V1 06, 2075 Bayview Avenue Toronto, ON M4N 3M5

Telephone: 416-480-4055

Email: communications@ices.on.ca