

# Provision of Moderately and Highly Effective Reversible Contraception to Insured Women With Intellectual and Developmental Disabilities

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**OBJECTIVE:** To estimate provision of moderately and highly effective reversible contraceptives to women with intellectual and developmental disabilities.

**METHODS:** We used data from the Massachusetts All-Payer Claims Database to identify women aged 15–44 years with and without intellectual and developmental disabilities who were continuously enrolled in a private

See related editorial on page 555.

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Justine Wu receives support from the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) under award number 1K23HD084744-01A1. Three of the authors (J.Z., M.M., S.L.P.) receive support from the NICHD of the National Institutes of Health under Award Number R01HD082105. This publication was also made possible by Grant Number R40MC30754 from the Health Resources and Services Administration, an operating division of the U.S. Department of Health and Human Services. Its contents are solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health, the Health Resources and Services Administration, or the U.S. Department of Health and Human Services. The funders had no role in the design and conduct of the study; collection, management, analysis, and interpretation of the data; preparation, review and approval of the manuscript; or decision to submit the manuscript for publication.

Each author has indicated that he or she has met the journal's requirements for authorship.

Received March 19, 2018. Received in revised form May 11, 2018. Accepted May 24, 2018.

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## Financial Disclosure

The authors did not report any potential conflicts of interest.

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ISSN: 0029-7844/18

commercial insurance plan, Medicaid, or Medicare in 2012. We calculated the percentage of women aged 15–44 years who were not medically or surgically sterile and were provided 1) highly effective, long-acting reversible contraception (LARC, the intrauterine device or subdermal implant); or 2) prescriptions for moderately effective methods (pill, patch, ring, shot, or diaphragm). Logistic regression models estimated the odds of LARC and moderately effective method provision by disability status, adjusted for age, income, and Medicaid receipt.

**RESULTS:** Among 915,561 women who were not medically or surgically sterile, 13,059 women (1.4%) had at least one intellectual and developmental disability. Women with intellectual and developmental disabilities were less likely to be provided LARC (2.1% vs 4.2%,  $P<.001$ , adjusted odds ratio [OR] 0.43, 95% CI 0.38–0.48,  $P<.001$ ) and moderately effective methods (21.1% vs 29.9%,  $P<.001$ , adjusted OR 0.68, 95% CI 0.65–0.71,  $P<.001$ ) than women without intellectual and developmental disabilities. The one exception was the progestin shot, which was provided more often to women with intellectual and developmental disabilities than women without these disabilities (14.7% vs 4.3%,  $P<.001$ ). Among a subset of women who only received moderately effective methods or LARC ( $n=310,344$ ), women with intellectual and developmental disability had lower odds of receiving LARC than moderately effective methods (adjusted OR 0.59, 95% CI 0.52–0.67).

**CONCLUSION:** The study findings raise concerns that the provision of LARC and moderately effective methods differs based on the presence of intellectual and developmental disabilities. Greater understanding is needed regarding factors that underlie lower provision of LARC in comparison with moderately effective methods,



especially the progestin shot, among women with intellectual and developmental disabilities.

(*Obstet Gynecol* 2018;132:565–74)

DOI: 10.1097/AOG.0000000000002777

An estimated 11.7% of reproductive-aged women in the United States have a disability that includes people with functional limitations related to vision, mobility, and ability to provide self-care and live independently, as defined by the Centers for Disease Control and Prevention.<sup>1</sup> Despite common and longstanding misconceptions, women with disabilities are sexually active and have reported similar or greater odds of sexual activity than their counterparts without disabilities.<sup>2–4</sup> A recent analysis of the 2008–2012 Medical Expenditure Panel Survey revealed that women with and without disabilities also reported similar proportions of pregnancy.<sup>5</sup> Another study of the Rhode Island Pregnancy to Risk Assessment Monitoring System found that women with disabilities were more likely to have an unintended pregnancy compared with their peers without disabilities.<sup>6</sup> These findings indicate the importance of contraceptive counseling and provision for women with disabilities who are not actively seeking pregnancy.

Among all women with disabilities, the contraceptive needs of women with intellectual and developmental disabilities are most poorly understood because this group has been underrepresented in prior U.S. contraceptive studies.<sup>7,8</sup> Assessing the contraceptive patterns of women with intellectual and developmental disabilities is critical because of their unique needs that may influence their access to contraception. Women with intellectual and developmental disabilities have reported inadequate contraceptive knowledge, limited communication with their health care team regarding contraception, and a lack of accessible informational materials regarding contraception.<sup>9,10</sup> Although the National Survey for Family Growth provides critical population-based data and trends regarding contraceptive use in the United States, this household-based survey does not capture people who live in institutional settings (eg, long-term care facilities)<sup>11</sup>; furthermore, the methods used to conduct this survey do not provide accommodations for women who may need communication assistance (eg, help from a caretaker, American Sign Language interpreter).<sup>11</sup> As a result, women with disabilities may be disproportionately excluded from these survey data.

To address these survey research limitations, we analyzed data from the 2012 Massachusetts All-Payer Claims database. This approach does not rely on self-report and capitalizes on a set of robust codes that permit identification of individuals with intellectual and developmental disabilities and contraceptive codes that

represent services and supplies accessed across multiple care settings.<sup>12</sup> The study aim was to compare the percentage of fertile, reproductive-aged women with and without intellectual and developmental disabilities and who were provided long-acting reversible contraception (LARC; intrauterine device or implant) or prescriptions for moderately effective contraceptive methods (pill, patch, ring, shot, or diaphragm).

## MATERIALS AND METHODS

We used data from the Massachusetts All-Payer Claims Database, a central repository of statewide health care claims data. The first release of the Massachusetts All-Payer Claims Database was in 2012 with individual-level medical and pharmacy claims data from commercial insurers, self-insurance, Medicaid, and Medicare dating back to 2009.<sup>12</sup> This data set provides a useful benchmark because Massachusetts has an extremely high percentage of insured people (97.3%) as a result of sweeping health care reform in 2006 and served as a model for the federal 2010 Patient Care and Affordable Care Act.<sup>13</sup> To report findings that can be used by payers, health care systems, federal and state agencies, and researchers,<sup>14</sup> we calculated contraceptive quality measures in a manner consistent with recommendations from the U.S. Department of Health and Human Services' Office of Population Affairs<sup>15</sup> and endorsed by the National Quality Forum in 2017.<sup>16</sup>

For these analyses, we selected data from 2012 because it contained the most robust and complete data set of the variables of interest compared with prior years of the Massachusetts All-Payer Claims Database. Commercial carriers and public programs submit data to the Massachusetts Center for Health Information and Analysis, which subjects these publicly available data to more than 1,000 programmed edits to ensure that diagnosis, procedure, and billing codes are verified against national standards; identification elements and demographics are verified; and claims have associated diagnosis codes.<sup>12</sup> The Massachusetts All-Payer Claims Database includes data from the majority of Massachusetts residents except for coverage provided by workers' compensation, TRICARE and the Veterans Health Administration, Federal Employees Health Benefit Plan, or uninsured individuals who are not enrolled in the Health Safety Net (ie, the state's trust, which pays for certain essential services for low-income patients).

To identify the eligible population of enrollees who are presumably fertile and at risk for pregnancy, we used methods and codes recommended by the U. S. Department of Health and Human Services Office of Population Affairs for International Classification



of Diseases, 9th Revision, Clinical Modification (ICD-9-CM) and Current Procedural Terminology codes, Healthcare Common Procedure Coding System codes (eg, “J” codes, “S” codes), and National Drug Codes.<sup>15</sup>

We started by identifying all women aged 15–44 years who were continuously enrolled in an insurance plan for 320 days or greater during 2012 and who had at least one claim identified in 2012. To isolate a cohort of women who was presumably fertile (the denominator for the contraceptive measures), we excluded women who were infecund for any identifiable medical (eg, menopause) or surgical reason (eg, hysterectomy, tubal sterilization, oophorectomy), currently pregnant, or recently pregnant (unknown pregnancy outcome at the end of the calendar year or who had a pregnancy that ended in a live birth in the last 2 months of the calendar year). For the purposes of these analyses, we refer to these women as “fertile.”

From this cohort of fertile women, we identified women with intellectual and developmental disabilities using methods and diagnosis codes described elsewhere.<sup>17,18</sup> Briefly, women were characterized as having an intellectual and developmental disability if they had at least one inpatient or emergency visit or two or more outpatient visits with at least 1 of 22 diagnostic codes that included but were not limited to cerebral palsy, Down syndrome, fetal alcohol syndrome, and autism spectrum disorder.

Among fertile women with and without intellectual and developmental disabilities, we identified the most recent contraceptive claim in 2012 based on appropriate ICD-9-CM codes, Current Procedural Terminology codes, Healthcare Common Procedure Coding System codes, and National Drug Codes for the pill, patch, ring, shot, diaphragm, intrauterine device, or implant. Using these codes, we calculated two contraceptive measures represented in percentages: 1) the number of fertile women aged 15–44 years who were provided a LARC device and 2) the number of fertile women aged 15–44 years who were prescribed a moderately effective contraceptive method (pills, patch, ring, shot, or diaphragm). Women who had a LARC device removed in the index calendar year but did not receive another LARC device or were not prescribed a moderately effective contraceptive either 30 days before or any time after LARC removal were not included in the numerator of either of these measures.

We determined the following socioeconomic data for all individuals in the cohort, regardless of disability status: age (15–19, 20–24, 25–34, or 35–44 years), Medicaid status (yes or no), and household income

(less than \$50,000, \$50,000–74,999, \$75,000–99,999, or \$100,000 or greater). Other variables commonly associated with contraceptive use such as race and ethnicity and parity could not be determined because these data were missing for more than 70% of the sample.

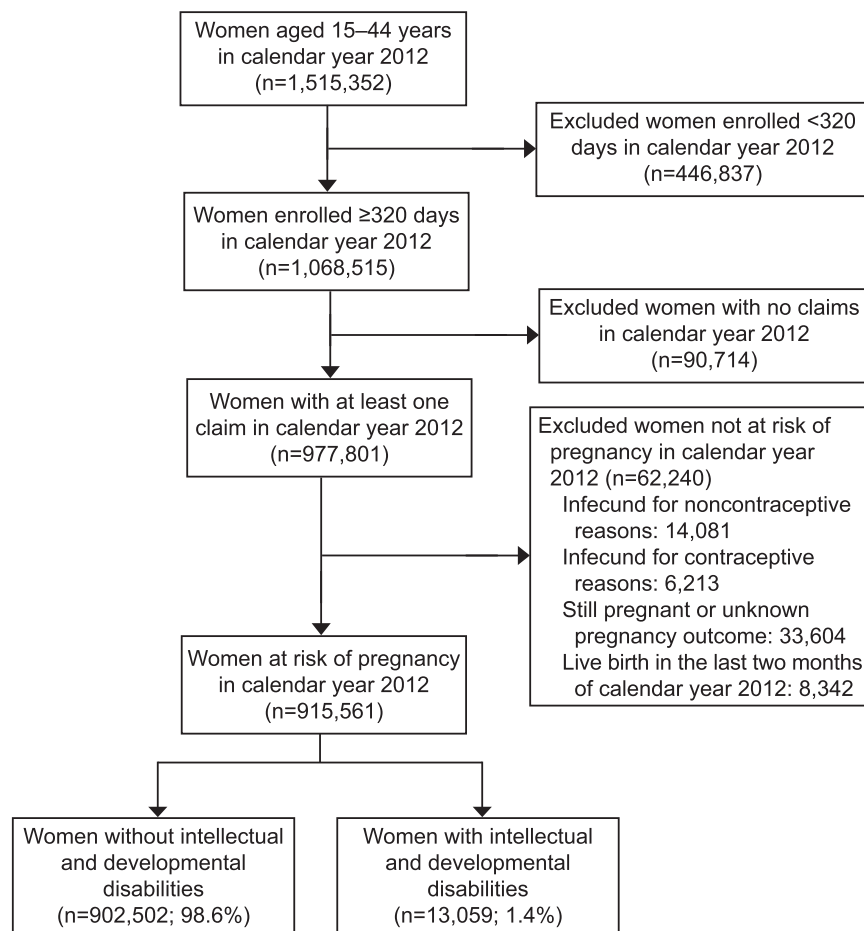
Using SAS 9.3, we calculated  $\chi^2$  to compare the distribution of sociodemographic characteristics and provision of LARC or prescription of moderately effective methods between women with and without intellectual and developmental disabilities. Logistic regression models estimated the odds of provision of LARC (reference=not provided LARC) or moderately effective methods (reference=no prescription for moderately effective methods) among all fertile women ( $N=915,561$ ) after adjusting for age, household income, and Medicaid status. We also calculated a model that included women who were only provided LARC or prescribed moderately effective methods ( $n=310,344$ ) to compare the odds of LARC provision (reference=provision of moderately effective methods) by disability (reference=absence of intellectual and developmental disability). The institutional review boards of Brandeis University, the Massachusetts Department of Public Health, and the Massachusetts Center for Health Information and Analysis approved the study. We set  $\alpha$  at  $<0.01$ .

## RESULTS

Among 1,515,352 Massachusetts women aged 15–44 years enrolled in a health plan in 2012, 977,801 were continuously enrolled in a health plan for at least 320 days and had at least one medical claim (Fig. 1). After excluding infecund women, there were 915,561 remaining among whom 13,059 had intellectual and developmental disabilities (1.4%) and 902,502 did not have such disabilities (98.6%). Among all 915,561 fertile women, 37,810 (4.13%) were provided LARC, 272,534 (29.8%) were prescribed moderately effective methods, and 605,217 (66.1%) were provided neither LARC nor moderately effective methods (Fig. 2).

Bivariate analyses revealed that women with intellectual and developmental disabilities were younger overall than women without such disabilities (Table 1). More than one third (34.4%) of women with intellectual and developmental disabilities were aged 15–19 years compared with 16.2% of their counterparts without intellectual and developmental disabilities ( $P<.001$ ). A significantly higher percentage of women with intellectual and developmental disabilities were Medicaid recipients than other women (78.1% vs 30.6%,  $P<.001$ ).





**Fig. 1.** Defining eligible population of women at risk for unplanned pregnancy.

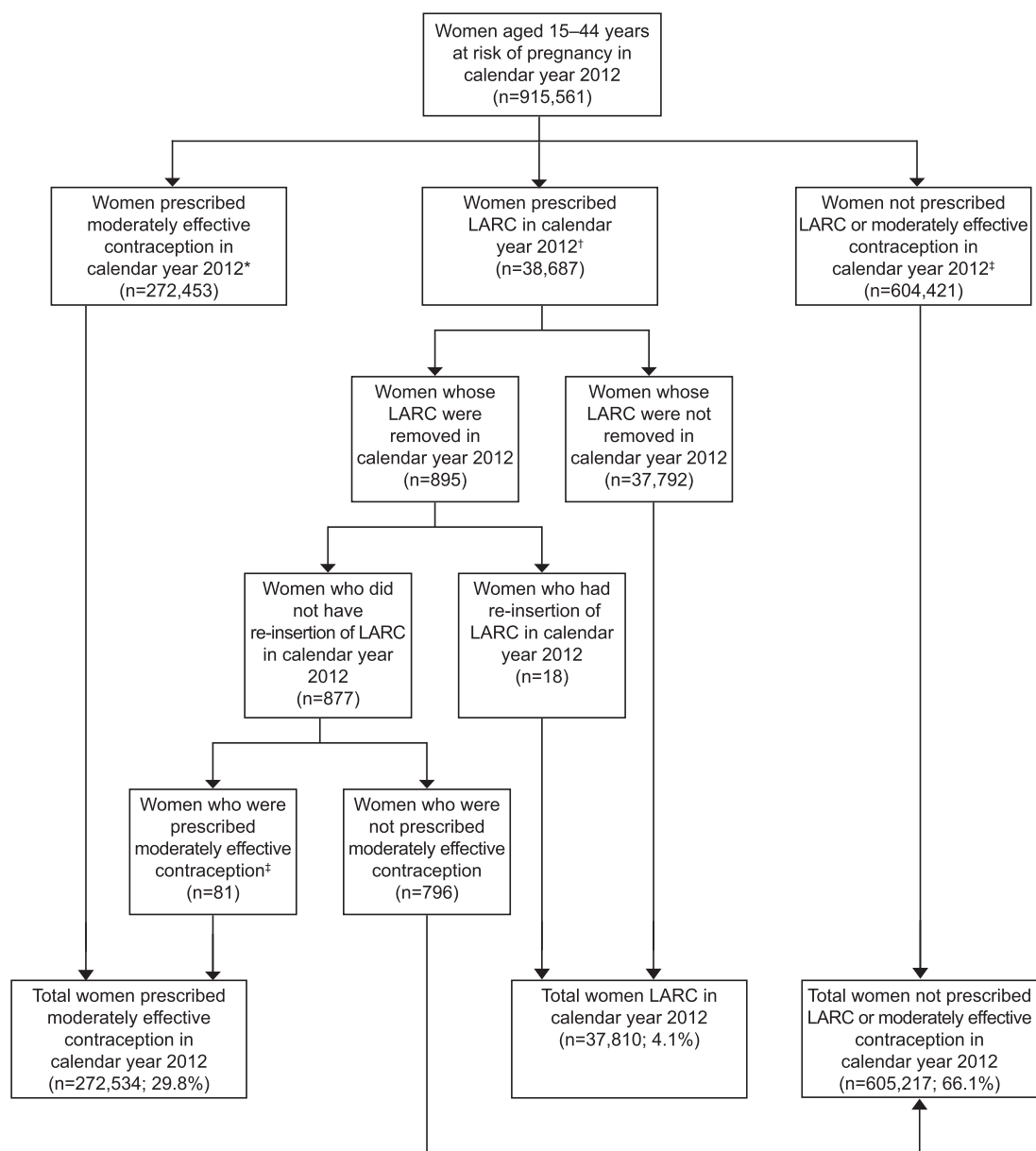
Wu. Contraceptive Provision for Women With Disabilities. *Obstet Gynecol* 2018.

Among women with intellectual and developmental disabilities, the most common ICD-9-CM codes captured, which were not mutually exclusive, were “intellectual disability” (formerly referred to as “mental retardation”; 75.4%) followed by “other genetic conditions” (38.6%, eg, Fragile X syndrome, Prader-Willi syndrome, Cri-du-chat syndrome) and cerebral palsy (25.2%) (results not shown).

Women with intellectual and developmental disabilities were provided moderately effective methods less frequently than their peers without such disabilities (21.2% vs 29.9%,  $P<.001$ ; Table 2). Among those provided moderately effective methods, the progestin shot was provided significantly more often for women with intellectual and developmental disabilities than those without such disabilities (14.7% vs 4.3%, respectively,  $P<.001$ ). Although overall LARC provision was low, the percentage of women with intellectual and developmental disabilities provided LARC was half that of women without intellectual and developmental dis-

abilities (2.1% vs 4.2%,  $P<.001$ ). After adjusting for age, household income, and Medicaid status in logistic regression models, the overall findings were consistent with bivariate findings (Tables 3 and 4). Compared with women without intellectual and developmental disabilities, women with intellectual and developmental disabilities had significantly decreased adjusted odds of being provided LARC (adjusted odds ratio [OR] 0.43, 95% CI 0.38–0.48,  $P<.001$ ) or being prescribed moderately effective methods (adjusted OR 0.68, 95% CI 0.65–0.71,  $P<.001$ ). In a regression analysis that included women who were only provided LARC or moderately effective methods, the adjusted odds of LARC provision was lower (adjusted OR 0.59, 95% CI 0.52–0.67,  $P<.001$ ) among women with intellectual and developmental disabilities compared with those without intellectual and developmental disabilities (Table 5). Fewer than 1% of all women were identified as having undergone female sterilization, precluding any meaningful comparisons with LARC use (results not shown).





**Fig. 2.** Defining the numerator for contraceptive measures using the patient's most recent contraceptive claim of calendar year 2012. \*Moderately effective methods include pill, ring, patch, progestin shot, or diaphragm. †Long-acting reversible contraceptive (LARC) methods include intrauterine devices or the implant. ‡This was identified by looking for a prescription of moderately effective contraception 30 days before LARC removal or any time after LARC removal until the end of calendar year 2012.

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## DISCUSSION

Our study showed that women with intellectual and developmental disabilities were less likely to be prescribed moderately effective contraceptive methods and provided LARC than their peers without intellectual and developmental disabilities. These findings raise concerns that contraceptive provision differs based on the presence of an intellectual or develop-

mental disability. These findings are consistent with a prior population-based study reporting that U.S. women with physical or sensory disabilities were less likely to use LARC and moderately effective methods than women without these disabilities.<sup>8</sup> The magnitude of these associations was greater in this study of women with intellectual and developmental disabilities, which may partially reflect confounders



**Table 1. Demographics of Fertile\* Women Aged 15–44 Years<sup>†</sup> by Intellectual and Developmental Disability Status (N=915,561)**

Characteristic	Women Without IDD	Women With IDD	P
Total (N=915,561)	902,502	13,059	
Age group (y)			<.001
15–19	145,776 (16.2)	4,495 (34.4)	<.001
20–24	157,706 (17.5)	2,377 (18.2)	.030
25–34	293,580 (32.5)	3,110 (23.8)	<.001
35–44	305,440 (33.8)	3,077 (23.6)	<.001
Medicaid recipient			<.001
No	626,054 (69.4)	2,865 (21.9)	
Yes	276,448 (30.6)	10,194 (78.1)	
Annual household income (\$)			<.001
Less than 50,000	54,958 (6.1)	1,132 (8.7)	<.001
50,000–74,999	231,810 (25.7)	4,008 (30.7)	<.001
75,000–99,999	249,778 (27.7)	4,108 (31.5)	<.001
100,000 or greater	239,189 (26.5)	3,288 (25.2)	<.001
Missing	126,767 (14.1)	523 (4)	<.001

IDD, intellectual and developmental disability.

Data are n (%) unless otherwise specified.

\* Fertile refers to women who were deemed not medically sterile (eg, menopause) or surgically sterile (eg, hysterectomy, oophorectomy, tubal ligation).

<sup>†</sup> Among women insured in Massachusetts who meet the inclusion criteria as detailed in Figure 1.

associated with contraceptive use such as race, ethnicity, parity, sexual activity, and pregnancy intentions that could not be examined in these analyses.

Unmeasured factors that are unique to women with intellectual and developmental disabilities may also have contributed to the noted associations and the observed magnitude of effect. Cross-sectional surveys and qualitative studies indicate that health care providers lack adequate knowledge, experi-

ence, and training to care for people with intellectual and developmental disabilities and are even less prepared to address the sexual and reproductive health needs of this population.<sup>19,20</sup> Caregivers, including family members and residential facility staff, play an important role in contraceptive selection and access, particularly for women who have moderate or severe disabilities, communication difficulties, and need or prefer to be accompanied to

**Table 2. Contraceptive Methods Among Fertile\* Women Aged 15–44 Years by Intellectual and Developmental Disability Status (N=915,561)**

Contraceptive Method	Women Without IDD (n=902,502 [98.6%])	Women With IDD (n=13,059 [1.4%])	P
LARC <sup>†</sup>	37,537 (4.2)	273 (2.1)	<.001
Moderately effective <sup>‡</sup>	269,783 (29.9)	2,751 (21.1)	<.001
Neither LARC nor moderately effective	595,182 (66.0)	10,035 (76.8)	<.001
Distribution of moderately effective methods only (n=272,534)			
Progestin shot	11,479 (4.3)	405 (14.7)	<.001
Pill	236,958 (87.8)	2,229 (81.0)	<.001
Patch	4,332 (1.6)	Greater than 50 (>2)	NA <sup>§</sup>
Ring	16,478 (6.1)	Greater than 50 (>2)	NA
Diaphragm	536 (0.2)	Less than 11 (<1)	NA

IDD, intellectual and developmental disability; LARC, long-acting reversible contraception; NA, not applicable.

Data are n (%) unless otherwise specified.

\* Fertile refers to women who were deemed to be not medically sterile (eg, menopause) or surgically sterile (eg, hysterectomy, oophorectomy, tubal ligation).

<sup>†</sup> LARC methods include intrauterine devices or the implant.<sup>‡</sup> Moderately effective methods include pill, ring, patch, progestin shot, or diaphragm.<sup>§</sup> As a result of low numbers of women with IDD prescribed the patch, ring, or diaphragm, exact numbers could not be reported to protect confidentiality; consequently P values could not be reported for these methods.

**Table 3. Odds of Long-Acting Reversible Contraception\* Provision Compared With No Long-Acting Reversible Contraception Provision Among Fertile† Women Aged 15–44 Years (N=915,561)**

	OR (95% CI)	P
IDD status‡		
IDD	0.49 (0.44–0.56)	<.001
No IDD	Referent	
IDD status§		
IDD	0.43 (0.38–0.48)	<.001
No IDD	Referent	
Age (y)§		
15–19	0.48 (0.47–0.50)	<.001
20–24	Referent	
25–34	1.02 (0.99–1.05)	.303
35–44	0.65 (0.63–0.67)	<.001
Medicaid recipient§		
Yes	1.57 (1.53–1.60)	<.001
No	Referent	
Income (\$)§		
Less than 50,000	1.25 (1.20–1.31)	<.001
50,000–74,999	1.22 (1.18–1.26)	<.001
75,000–99,999	1.05 (1.02–1.08)	.002
100,000 or greater	Referent	

OR, odds ratio; IDD, intellectual and developmental disability; LARC, long-acting reversible contraception.

\* LARC methods include intrauterine devices or the implant.

† Fertile refers to women who were deemed not medically sterile (eg, menopause) or surgically sterile (eg, hysterectomy, oophorectomy, tubal ligation).

‡ Unadjusted.

§ Adjusted.

**Table 4. Odds of Being Prescribed Moderately Effective Methods\* Compared With Not Being Prescribed Moderately Effective Methods Among Fertile† Women Aged 15–44 Years (N=915,561)**

	OR (95% CI)	P
IDD status‡		
IDD	0.63 (0.60–0.65)	<.001
No IDD	Referent	
IDD status§		
IDD	0.68 (0.65–0.71)	<.001
No IDD	Referent	
Age (y)§		
15–19	0.70 (0.69–0.71)	<.001
20–24	Referent	
25–34	0.60 (0.59–0.61)	<.001
35–44	0.18 (0.18–0.18)	<.001
Medicaid recipient§		
Yes	0.52 (0.51–0.52)	<.001
No	Referent	
Income (\$)§		
Less than 50,000	0.68 (0.67–0.70)	<.001
50,000–74,999	0.82 (0.81–0.83)	<.001
75,000–99,999	0.96 (0.95–0.97)	<.001
100,000 or greater	Referent	

OR, odds ratio; IDD, intellectual and developmental disability.

\* Moderately effective methods include pill, ring, patch, progestin shot, and diaphragm.

† Fertile refers to women who were deemed not medically sterile (eg, menopause) or surgically sterile (eg, hysterectomy, oophorectomy, tubal ligation).

‡ Unadjusted.

§ Adjusted.

medical visits.<sup>9,10</sup> There is evidence that caregivers request contraception on behalf of women with intellectual and developmental disabilities for noncontraceptive reasons, including menstrual-related behavioral concerns, hygiene concerns, or both or preventing pregnancy in the event of sexual assault.<sup>9,21,22</sup> This latter concern is probably driven by the markedly higher rate of sexual abuse and assault among women with intellectual and developmental disabilities compared with other women.<sup>23</sup> The extent to which caregivers and health providers discuss contraception with women with intellectual and developmental disabilities to prevent pregnancy from consensual sexual activity or to plan a family is poorly understood.<sup>24</sup> Societal assumptions that women with intellectual and developmental disabilities are neither interested in sex<sup>24,25</sup> nor physically or emotionally capable of parenting<sup>26</sup> are pervasive. These collective stereotypes may then lead to false assumptions that family planning services, including contraceptive counseling and provision, are not necessary for this population.

When women with intellectual and developmental disabilities were provided a contraceptive method, they are more likely to be provided a moderately effective method than a LARC device. Furthermore, women with intellectual and developmental disabilities were more likely to be provided the progestin shot compared with their nondisabled peers. This difference may reflect caregiver and health care provider preference for the progestin shot because of its ease of administration and associated menstrual suppression.<sup>27</sup> Menstrual suppression can be used to treat conditions such as menorrhagia, behavioral changes during menses, anemia secondary to menstrual loss, dysmenorrhea, and menstrual headaches.<sup>21</sup> However, decisions to recommend or select the shot for hygiene purposes alone or for the convenience of family members and caregivers must be carefully weighed against potential disadvantages, including weight gain, acne, and decreased bone mineral density, side effects for which women with intellectual and developmental disabilities are already at increased risk.<sup>21</sup> It is possible that greater use of the progestin shot could have been



**Table 5. Odds of Using Long-Acting Reversible Contraception\* Compared With Using Moderately Effective Methods† Among Fertile‡ Prescription Contraceptive Users§ Aged 15–44 Years (n=310,344)**

	OR (95% CI)	P
IDD status <sup>  </sup>		
IDD	0.71 (0.63–0.81)	<.001
No IDD	Referent	
IDD status <sup>¶</sup>		
IDD	0.59 (0.52–0.67)	<.001
No IDD	Referent	
Age (y) <sup>¶</sup>		
15–19	0.57 (0.55–0.60)	<.001
20–24	Referent	
25–34	1.43 (1.38–1.47)	<.001
35–44	2.39 (2.31–2.46)	<.001
Medicaid recipient <sup>¶</sup>		
Yes	2.54 (2.47–2.60)	<.001
No	Referent	
Income (\$)¶		
Less than 50,000	1.68 (1.60–1.76)	<.001
50,000–74,999	1.39 (1.35–1.44)	<.001
75,000–99,999	1.09 (1.05–1.12)	<.001
100,000 or greater	Referent	

OR, odds ratio; IDD, intellectual and developmental disability; LARC, long-acting reversible contraception.

\* LARC methods include intrauterine devices or the implant.

† Moderately effective methods include pill, ring, patch, progestin shot, or diaphragm.

‡ Fertile refers to women who were deemed not medically sterile (eg, menopause) or surgically sterile (eg, hysterectomy, oophorectomy, tubal ligation).

§ Prescription contraceptive users are defined as the sum of women using LARC and women using a moderately effective method.

<sup>||</sup> Unadjusted.

<sup>¶</sup> Adjusted.

partially driven by significant racial and ethnic differences (which we could not examine in these analyses) between women with and without intellectual and developmental disabilities because there is evidence that a higher percentage of non-Hispanic black women use the shot compared with Hispanic women and non-Hispanic white women.<sup>28</sup>

Other barriers to contraceptive access that have been reported for women with physical or sensory disabilities are likely similar to those faced by women with intellectual and developmental disabilities. A major obstacle includes the lack of fully accessible facilities, which the Americans With Disabilities Act defines as being equipped not only for physical access (eg, adjustable tables, staff trained in safe transfers), but also for effective communication (eg, use of visual aids for those with low literacy, providing more time during office visits).<sup>29</sup> Lack of experience performing pelvic exams and LARC procedures for women with

intellectual and developmental disabilities may discourage clinicians from routinely discussing these contraceptive methods with caregivers and patients.<sup>30</sup> Unfortunately, formal medical education about the needs of people with disabilities is limited, although some schools have implemented training with standardized patients with disabilities.<sup>31,32</sup> Educational interventions to improve health care provider skills in gynecologic care for women with disabilities exist such as the American College of Obstetricians and Gynecologists' online resource suite and should be evaluated for effect on knowledge and practice<sup>33</sup> for women with intellectual and developmental disabilities.

There were several study strengths related to the use of the Massachusetts All-Payer Claims Database. This data set includes claims not only from private payers, but also Medicare and Medicaid, which are critical sources of health insurance for people with disabilities in Massachusetts.<sup>12</sup> We identified that 1.4% of fertile women aged 15–44 years had at least one intellectual and developmental disability diagnosis, which is consistent with a prior national estimate that 1.3% of all U.S. women have intellectual and developmental disabilities.<sup>34</sup> Massachusetts is a unique state because the vast majority of its residents have had insurance coverage since 2006.<sup>12</sup> Massachusetts was also 1 of 26 states in 2012, the index year of this analysis, that mandated insurer coverage of contraceptives approved by the U.S. Food and Drug Administration.<sup>35</sup> Thus, this study's estimates are useful benchmarks for comparisons with states that have higher rates of underinsured and uninsured individuals or broader exemptions to mandated contraceptive coverage. Finally, the use of carefully selected diagnostic codes was more likely to generate a cohort of women with moderate to severe intellectual and developmental disabilities who are less likely to be represented in national household surveys that exclude institutional settings.

The use of insurance claims data has methodologic limitations. First, the analytic sample included only women with continuous coverage for 320 days or greater, per U.S. Department of Health and Human Services recommendations,<sup>15</sup> to maximize the data available to calculate contraceptive quality measures. Thus, women who had lapses in coverage are less likely to be represented in the sample. Additionally, our estimated LARC provision is lower than previously estimated LARC use based on survey data because 1) women who are not at risk for pregnancy can be removed from the denominator and 2) women can report LARC insertions that occurred in prior





years (in this study, our data were limited to 1 year of claims). Furthermore, we could not account for sexual activity or pregnancy intentions, which are important determinants of contraceptive behavior.<sup>36</sup> Ideally, women who were not actively seeking pregnancy or who had not had heterosexual activity in the index year would have been removed from the cohort. We were unable to examine the effect of other potential confounders of contraceptive use such as race-ethnicity, parity, and education.<sup>36</sup> However, a recent nationally representative study did not find differences in LARC use based on race and ethnicity alone.<sup>36</sup> With respect to parity, epidemiologic studies have shown that a higher percentage of parous women use LARC and a lower percentage of parous women use the pill when compared with nulliparous women.<sup>28</sup> If there were significant differences in parity between women with and without intellectual and developmental disabilities in this cohort, this could affect the observed difference in LARC use. Claims for contraceptive services and prescriptions are proxies for behavior and may not reflect actual contraceptive use. However, codes for LARC placement and removal should be reliable because they reflect procedural codes and not patient behavior. Regardless of disability status, women who had LARC devices placed before 2012 were not counted in the numerator. As a result of the use of diagnostic codes, it is also possible that women with mild intellectual and developmental disabilities who might not have been officially diagnosed by a clinician would not have been included in this analysis. As a result of overlapping ICD codes and small samples for some groups, meaningful comparisons across subgroups of women with intellectual and developmental disabilities was not feasible. Women without a diagnosis of intellectual and developmental disability may be less likely to seek medical care and have a medical claim and thus not be included in the denominator; this may have led to overestimation of contraceptive provision to women without intellectual and developmental disabilities. When considering LARC provision, it is useful to compare it with female sterilization use, because these are both important contraceptive options for women who desire long-term (and possibly indefinite) contraception and recent nationally representative data show that use of female sterilization has decreased, whereas LARC use has concomitantly increased.<sup>36</sup> However, fewer than 1% of women in this analysis were identified as having undergone female sterilization, which represents a gross underestimate compared with a recent national estimate that 22% of all contraceptive users

have undergone female sterilization and precludes meaningful comparisons.<sup>36</sup> An analysis with more years of data may have identified sterilization procedures that occurred before the index year, but reliable and robust data before 2012 were not available. Findings from another insurance claims analysis reported a similarly low rate of female sterilization (1.7%) among women with medical conditions despite including sterilization claims several years before the index year.<sup>37</sup>

Despite these limitations, this analysis provides contraceptive quality measures for women with intellectual and developmental disabilities in a manner consistent with national reporting standards. These estimates can be used as a benchmark for tracking and comparing contraceptive provision to women with intellectual and developmental disabilities across states and nationally. To obtain the most accurate estimates of contraceptive use, there is still a need for primary data collection that oversamples for women with intellectual and developmental disabilities who are underrepresented in household surveys such as those who reside in long-term care facilities. Topics that warrant future investigation include factors that underlie lower provision of LARC and moderately effective methods, yet higher provision of the shot, among women with intellectual and developmental disabilities.

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