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Contraceptive Practices and Reproductive Health Considerations for Adolescent and Adult Women with Intellectual and Developmental Disabilities: A Review of the Literature

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Abstract

Whereas progress has been made on increasing access to comprehensive healthcare for individuals with intellectual and developmental disabilities (I/DD), disparities continue in health outcomes, including those related to the reproductive health of adolescent and adult women with I/DD. This review summarizes reproductive care considerations for adolescent and adult women with I/DD and current practices regarding the delivery of contraceptive services to these women. Forty-seven (47) articles based on research conducted in the US between 1999 and 2019 were selected for inclusion in the review. Primary themes discussed include (1) common reproductive health concerns for adolescent and adult women with I/DD, other than pregnancy prevention; (2) contraceptive methods and disability-related concerns; (3) informed consent and reproductive decision-making; and (4) provider knowledge and education. The management of menses and hormonal dysregulation were identified as concerns that providers encounter among patients with I/DD and their families. Disability-related concerns with regard to use of contraception in general and considerations regarding certain methods in particular include challenges with prescription adherence, physical effects of hormonal therapies, drug interactions for individuals with additional health conditions, and legal and ethical concerns involved with decision-making and consent. The results of this review also suggest that focused efforts in partnership with health care providers may be needed to address barriers that adolescent and adult women with I/DD face when trying to obtain quality reproductive health services and contraceptive guidance.

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Disclaimer: The findings and conclusions in this report are those of the author(s) and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

Keywords

Contraception; Intellectual disability; Developmental disability; Reproductive health; Family medicine; Primary care; United States

Introduction

Reproductive health care for adolescent and adult women with intellectual and developmental disability (I/DD) has been marked historically by practices of segregation, institutionalization, and stigmatization [1–4]. With the establishment of legal protections (e.g., Americans with Disabilities Act (ADA) of 1990 [5] and the U.S. Supreme Court's landmark Olmstead decision in 1999 [6], which promoted the delivery of health care services in community rather than institutional settings for individuals with disability), social inclusion and health outcomes generally have improved for individuals with I/DD [7, 8]. However, adolescent and adult women with I/DD continue to experience health disparities [9, 10], including reproductive health disparities [11], such as unintended pregnancy, sexual victimization, and limited access to reproductive health care [9–26].

I/DD is often used to describe individuals who have both intellectual disabilities and other developmental disabilities, such as Down syndrome and Fragile X syndrome. Intellectual disability (ID) refers to a group of disorders characterized by limited mental capacity and associated difficulties with adaptive behaviors such as managing schedules, routines, and social interactions [27, 28]. The term developmental disability (DD), which encompasses intellectual disability (ID), is a broad category of disability caused by mental or physical impairment or a combination of both [29]. Individuals with I/DD may demonstrate problems with learning; self-care; language skills, including expression and understanding; and independent living [27–29].

Access to quality health care for individuals with I/DD has been a public health concern since the deinstitutionalization of this population, which began in the 1950s and was accelerated by the Olmstead decision 20 years ago [6]. Although population-based data on the health of people with I/DD remain scarce, recent studies indicate a combination of continuing disparities in reproductive health outcomes and poor access to reproductive health care among adolescent and adult women with I/DD [9–26]. Contraception plays an important role in reproductive health care for adolescent and adult women with I/DD, helping both to reduce unintended pregnancy and address possible need for menstrual suppression or regulation [30–32]; therefore, contraceptive service provision may be a specific area of focus for improvement. To inform such improvement, we performed a literature review to summarize contraceptive practices and reproductive health considerations related to adult and adolescent women with I/DD.

Methodology

We limited this review to the Medline PubMed database. A public health librarian experienced in reproductive health and disability advised on the development of the search string and Medical Subject Headings (i.e., MeSH terms; "Appendix 1") and conducted the initial database search. PubMed search terms included combinations of the following: “intellectual disability,” “developmental disabilities,” “mental retardation,” “autism,” “Down syndrome,” “contraceptive agents and devices,” “contraception behavior,” “contraception,” “female,” and “women.”

We limited articles to those that reported on U.S.-based research and were published in English from January 1999 through April 2019. The first author [JV] reviewed titles and abstracts to ascertain whether initially identified articles discussed the population of interest and met criteria for inclusion. Language describing individuals with I/DD has undergone change in the last two decades. Phrases such as mental retardation, learning disabled, and special needs population, among others, have been used to describe and categorize individuals with I/DD. Additionally, I/DD is a broad category of disability. Individuals with I/DD may be clinically identified with a variety of disorders (e.g., Angelman syndrome, Down syndrome, autism, cerebral palsy) and may experience both cognitive and physical impairment [27–29]. Search and inclusion strategies reflected these variations and historically-used population descriptors.

Titles, key words, and abstracts were reviewed to identify articles relevant to the population of interest (i.e., adolescent and adult women with I/DD). Based on targeted search terms, 658 publications were identified for initial review. Application of inclusion criteria resulted in the inclusion of forty-seven articles in the final review. Selected articles consisted of 19 studies (Table 1) and 28 clinical resources (Table 2), such as clinical reports, commentaries, and reviews.

These articles were examined using an inductive approach [33, 34], which involved close reading, annotation, and summarization of articles, as well as analytic memoing. Co-authors met regularly to discuss articles, to explore differences in interpretations and allow peer-checking of assumptions. These discussions informed rereading of articles and the development of overarching themes through constant comparison [33] of consistencies and differences found through reading and discussion.

Results

Four overarching, inductively-derived thematic categories were identified: (1) common reproductive health concerns, other than pregnancy prevention; (2) contraceptive methods and disability-related concerns; (3) informed consent and reproductive decision-making; and (4) provider knowledge and education.

Common Reproductive Health Concerns Other than Pregnancy Prevention

Menstrual Management and Suppression—Menses management was identified in multiple articles [35–44] as a primary reason patients with I/DD and their families seek reproductive health counseling from physicians. Parents and caregivers may approach physicians for menstrual regulation or suppression and seek anticipatory treatment prior to menarche [37, 39–42]. Patient difficulties with self-care may be factors that contribute to this pattern [43]. Patient and caregiver requests for counseling from health care providers were identified as opportunities to discuss reproductive health and provide anticipatory menstrual management guidance [35–46].

Management of Hormonal Dysregulation—In several articles [39, 40, 47–51], authors identified that adolescent and young women with I/DD may experience additional challenges with emotional regulation and behavior during menses. Menstrual-related behavioral and emotional concerns included excessive fatigue, crying, irritability, sadness, anxiety, and cramps as well as increases in behavioral symptoms (e.g., stimming) associated with some developmental disabilities. For example, by surveying caregivers of adolescent and adult women between ages 10 and 25 years who were diagnosed with autism spectrum disorder (ASD) about menstrual issues for the individuals in their care, one study [49] found 33% of respondents ($n = 29$) to report increases in ASD-specific symptoms such as repetitive movements and obsessive behaviors as well as increased aggression. Likewise in a retrospective review [47] of electronic medical records of 44 adolescents with Down syndrome, autism, and cerebral palsy receiving services at an outpatient gynecologic clinic, caregiver concerns were related to menstruation management and to associated patient mood changes, ranging from mild to more severe behaviors, including self-injury. There was also indication that hormonal contraceptives may be underutilized for potential treatment of dysmenorrhea and premenstrual symptoms for female youth with I/DD [46, 47]. Additional research to support clinical guidance for treatment of hormonal dysregulation for individuals with I/DD was recommended [47–51].

Contraceptive Methods and Disability-Related Concerns—Oral contraceptive pills (OCPs) [35, 37–41, 46, 52], the transdermal contraceptive patch [35, 39–41, 53], depo-medroxyprogesterone acetate (DMPA) [32, 35, 37–41, 53, 54], long-acting reversible contraception (LARC) methods [37, 38, 40, 41, 45, 55] and sterilization [32, 35, 37–39, 41] were discussed in the literature in relation to women with disabilities. Table 3 provides an overview of reported contraceptive method concerns related to adolescent and adult women with I/DD. Disability-related concerns included challenges with prescription adherence, medical risks of procedures, physical effects of hormonal therapies, drug interactions for individuals with additional health conditions, and legal and ethical concerns involved with decision-making and consent for contraceptive use and sterilization.

Oral Contraceptive Pills (OCPs)—Some investigators report that oral contraceptive pills (OCPs) are commonly prescribed to individuals with I/DD [30, 35]. However, in an analysis of Massachusetts' insurance claims data, women with I/DD were provided OCPs less frequently than peers without disabilities [56]. Factors associated with patterns of use were not investigated; however, some articles [37–40] identified cognitive limitations of patients with I/DD as barriers to the efficacious use of OCPs, with patients and caregivers noting challenges to maintaining the prescribed course. Several advantages to prescribing OCPs were also indicated, including few side effects and the reversible nature of the method [30, 35, 39].

Transdermal Contraceptive Patch—Some research [35, 39] suggested that the transdermal patch may be positively received by patients with I/DD as well as their caregivers, given the less frequent dosing required with the patch compared with daily OCPs. However, risks for venous thromboembolism (VTE), bone density loss, weight gain, skin reactions, and inadvertent removal were noted concerns [35, 39, 53].

Depo-Medroxyprogesterone Acetate (DMPA)—Depo-medroxyprogesterone acetate (DMPA), a progestin-only injectable contraception, may be used to achieve amenorrhea [35, 37, 53] and was described as convenient and easy to administer [37, 56]. There was some evidence of high DMPA use among women with I/DD with one population-based study [56] indicating that DMPA was more often provided to women with I/DD than women without disabilities. Several concerns related to DMPA usage for the I/DD population were noted in the literature, including bone mineral density loss [35, 37, 52, 54] and increased risk of fracture [35, 54]. Low mobility and weight gain were identified as additional factors to be considered for adolescents and women with I/DD [32, 35, 37, 52, 54], given increased risk for obesity in this population.

Long-Acting Reversible Contraception (LARC)—Evidence to support the use of LARC for the I/DD population was found in several articles [37, 41, 44, 45, 55, 57]. For example, a retrospective chart review [45] investigating experiences with the insertion procedures found few technical or surgical challenges for adolescent and adult women with I/DD. One reported concern noted in this study was chance of unsatisfactory fit and patient challenges with reporting discomfort because of communication limitations [45]. To ensure patients and caregivers had means to report discomfort or other problems and to support patient involvement in the decision-making and consent process, the need to establish strategies for communication among patients, caregivers, and providers was highlighted [45]. Even though evidence supporting the use of LARC for women with I/DD exists, women with I/DD were less likely to be provided LARC than women without disabilities and more likely to be provided a moderately effective method (i.e., pill, patch, injectable or ring) [56]. Factors that may underlie the lower provision of LARC to women with I/DD than to women without disabilities were not described.

Sterilization—Analyses of the 2011–2015 National Survey of Family Growth (NSFG) [58–60], the 2011–2013 NSFG [59], and the 2013 Behavioral Risk Factor Surveillance System (BRFSS) [61] revealed that, among sexually active women at risk for pregnancy, women with disabilities were more likely to use permanent methods of contraception, particularly female sterilization, than women without disabilities. Additionally, females with cognitive disabilities underwent sterilization at significantly younger ages than those with non-cognitive disabilities and those without disabilities [60].

Across the literature, discussions of medical, ethical, and legal considerations regarding sterilization recurred [30–32, 38–41, 57, 59–70], as did the importance of providing historical contextualization to healthcare providers [59, 62–64, 66]. Specifically discussed were the high numbers of forcible sterilizations that had been performed on individuals with I/ DD in the past [66–69]. The eugenics movement of the early twentieth century along with national legal precedence, including the 1927 US Supreme Court case of Buck v Bell [38, 66–69], were referenced as contributing to this practice, which is now considered discriminatory. State and federal protections for individuals with disability (e.g., Rehabilitation Act of 1973, Americans with Disability Act of 1990) were identified as helping to establish legal protection against the forced or coerced sterilization of women and female youth with I/DD [38, 66–69]. Some authors also report that parents of adolescent and adult women with I/DD may request sterilization [39–41, 67, 69] and that such requests for sterilization may arise out of reproductive health concerns, including challenges with menses management or lack of knowledge about other long-lasting, highly effective, reversible alternatives for pregnancy prevention.

Consent and Reproductive Decision-Making—Across many articles, reproductive health decision-making for individuals with I/DD was discussed [30, 38–44, 57, 65–67]. The support of menses management and compliance with prescriptions may be facilitated through greater inclusion of individuals with I/DD in the consent and treatment process [40, 41, 44, 47] and through provision of reproductive health education opportunities and materials [71–74] designed for individuals with I/DD. However, there is evidence to suggest that adolescent and adult women with I/DD may not receive reproductive health education [26, 31] and that adult women with I/DD may have less contraceptive knowledge than peers without I/DD [75].

Complexities involved in the determination of patients' best interests, in support of patient rights to access medically beneficial services, and in provision of supportive decision-making, especially related to sterilization, were also discussed [30–32, 38–41, 63, 76]. The American College of Obstetrics and Gynecology and the American Academy of Pediatrics have released policy statements [64, 70] that highlight the complex history of sterilization of adolescent and adult women with I/DD and that provide general recommendations related to decision-making for health care providers, including pediatricians, obstetrician-gynecologists, and family practice physicians. These statements also discuss legal considerations surrounding the use of sterilization for individuals with I/DD, alternatives for pregnancy prevention, and ways in which physician counseling practices along with disability status, race, ethnicity, and socioeconomic status may influence the decision-making process.

According to the American Academy of Pediatrics [71], developmentally appropriate and evidence-based reproductive health education can enhance responsible decision-making, which may have the potential to reduce risks of unintended pregnancy, sexually transmitted infections, and sexual coercion [71]. To ensure adequate understanding of reproductive health and sexual development, routine conversations about sexual development and reproductive health among clinicians, patients, and caregivers are encouraged [31, 32, 43, 72, 73]. Linking families to additional service providers with training on sexual health education for this population may assist in supporting patient needs while also serving to allay caregiver anxieties about menstrual management, hormonal dysregulation, and reproductive development [31, 32, 43, 73].

Both nursing professionals and social workers, who may be able to spend more time with patients and caregivers, were identified as suitable to lead or support communication and guide a supportive decision-making process [32, 67, 74]. Assistive communication devices and printed materials written at patients' cognitive level were both identified as potentially helping to address barriers to communication and issues concerning active patient consent [71–74, 77]. Use of pictures, cartoons, videos, dolls with anatomical parts, and opportunities for individuals to interact with teaching aids were described as important supports for the I/DD population along with materials to educate parents and caregivers [72–74, 77].

Provider Knowledge and Education—Clinicians report limited knowledge of reproductive health considerations for the I/DD population [78, 79]. Physician apprehension in meeting needs of patients with I/DD, lack of preparedness in routine screenings involved in gynecological care, and physician-reported inadequacies in preparation to address reproductive health topics for individuals with I/DD were documented [78, 79]. Lack of familiarity with individuals with I/DD, uncertainty of best practices and resources, and reported physician anxiety serving this population may affect clinical experiences for adolescent and adult women with I/DD [74, 76–81].

While guidance for healthcare providers on how to approach the provision of reproductive health care and education for individuals with I/DD exists [e.g., 43, 72–74, 77, 82–86], caregivers and providers may not recognize the sexuality of individuals with disability, including adolescent and adult women with I/DD, thus limiting patient access to education and family planning services that could support independent decision-making [43, 79, 87, 88]. Recommendations to enhance provider knowledge about serving adolescent and adult women with I/DD include the provision of continuing education experiences to build clinical skills and the incorporation of additional training into family practice, pediatric, and obstetric and gynecologic residency programs with more exposure to patients with I/DD [78, 79].

Discussion

This review summarizes clinical literature related to contraceptive practices and reproductive health considerations for adolescent and adult women with I/DD. This information may be used to inform efforts to address the reproductive health needs of adolescent and adult women with I/DD. In particular, the management of menses, self-care during menses, and hormonal dysregulation, including associated behavioral changes, are concerns that providers encounter among patients with I/DD and their families. Hormonal contraceptives may be under-utilized for potential treatment of dysmenorrhea and premenstrual symptoms for female youth with I/DD. No evidence contradicts the use of LARC for women with I/DD; however, research suggests LARC is less frequently used by women with I/ DD than by women without disability. Disability-related concerns with regard to use of contraception in general and considerations regarding certain methods in particular include challenges with prescription adherence (OCPs), physical effects of hormonal therapies, drug interactions for individuals with additional health conditions, patient challenges with reporting discomfort with LARC placement, and legal and ethical concerns involved with decision-making and consent.

Gaps in training on disability for health care practitioners and limited experience with and understanding of I/DD may serve as barriers to the receipt of appropriate and effective health care, including reproductive health care, especially in the transition from pediatric to adult care [74, 76–81]. Few professional health care training programs address disability considerations in their curricula or are required to demonstrate disability competency [89]. Consequently, physicians may lack the skills and experience necessary to ensure that needs of patients with I/DD are addressed and that patients are appropriately supported through decision making [78, 79]. National programs such as the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) and the Leadership Education in Adolescent Health (LEAH) aim to improve the provision of health care services for individuals with disability and offer advanced clinical training to health care providers [90]. Such initiatives are one way to build provider competencies and enhance preparedness to provide health care, including reproductive health care, to individuals with I/DD.

The American College of Obstetricians and Gynecologists (ACOG) calls for the provision of quality health care appropriate to the needs of women throughout life, including adolescent and adult women with I/DD [91, 92]. ACOG encourages providers to seek additional resources and expertise, especially when caring for patients with underlying genetic conditions [91], and to be aware of barriers to reproductive health care and education that adolescent and adult women with I/DD may experience [92, 93]. In addition to common issues related to the initiation and use of specific contraceptive methods [94, 95], additional considerations may apply to adolescent and adult women with I/DD. For example, indications for use of certain contraceptive methods [94, 95] may vary depending upon health conditions that commonly co-occur with I/DD, such as obesity [96] and seizure disorders [97] or elevated risks for specific I/DD sub-populations, e.g., deep vein thrombosis in individuals with severe motor disability in addition to I/DD [98].

ACOG also recommends that health education and gynecologic care be based on a patient's intellectual and physical capabilities, which may require the implementation of additional counseling strategies [91, 93]. In addition, the reproductive health needs of adolescent and adult women with I/DD, may be supported by initiatives to improve transition from pediatric to adult health care, such as the Got Transition™ program [99] and the Center for Health Care Transition Improvement funded by the Health Resources and Service Administration [90]. These initiatives provide recommendations for improving accessibility of health care services, including reproductive health services, and of health promotion and intervention initiatives.

The results of this review suggest that focused multi-disciplinary efforts may be needed to meet the reproductive health care needs of adolescent and adult women with I/DD. Such efforts could inform community-based, public health initiatives that promote the reproductive health of youth and adult women with I/DD through outreach and education [100]. Additionally, evidence-based reproductive health materials/aids designed for adolescent and adult women with I/DD and their caregivers, and/or referrals to service providers with training in sexual health education for individuals with I/DD could strengthen sexual and reproductive health support for this population. Individuals with I/DD have, historically, experienced challenges finding health care that is responsive to their distinctive needs, such as commonly experienced communication limitations [36, 63, 76]. Moreover, adolescent and adult women with I/DD may not be expected to need or use reproductive health services, because of historically established social stigmatization of the I/DD population, which may limit receipt of contraception for purposes either of pregnancy prevention or menstrual management and may result in the omission of this population from some research efforts [24, 63, 76, 88, 101, 102].

To confront barriers that adolescent and adult women with I/DD face when trying to obtain quality reproductive health services and contraceptive guidance, future research might seek to identify the unique reproductive care needs for this population [100]. For example, data gaps can be addressed, such as the prevalence of contraceptive use among women with I/DD living in congregate care settings, and additional research can be conducted to strengthen the evidence base for clinical guidance. The inclusion of additional disability questions to national data systems such as the BRFSS has potential to facilitate new population-based research in this area [103]. Additionally, the use of a combination of surveillance methods and multiple data sources, including administrative data and national and state data, may be used to further understanding of the reproductive health needs of adolescent and adult women with I/DD [104, 105]. As well, mixed methods research (qualitative and quantitative data collection and integration) and participatory action research (PAR) may be suited to better understanding of the complexities of lived experiences of adolescent and adult women with I/DD and to supporting their active involvement in research initiatives [63]. Identification of disability-specific needs, concerns, and complications associated with the provision of specific contraceptive methods to adolescent and adult women with I/DD can support the establishment of more informed, better prepared, and more finely coordinated systems of reproductive health care provision for this population [61, 63, 76, 101, 104, 105].

Appendix 1

Medical Subject Headings (MeSH) for PubMed Search

MeSH String: (intellectual disability OR persons with disabilities OR developmental disabilities OR autism OR autistic OR Asperger OR Down syndrome) AND (contraceptive agents, female OR contraceptive devices, female) OR (contraception OR contraception behavior) AND (female OR women).

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Table 1

Types of studies informing results of literature review

Types	Topics
Cross sectional population-based observational study	1. Depot medroxprogesterone use and fracture incidence in women with developmental disabilities[a] 2. Healthy behaviors and lifestyles in young adults with developmental disabilities[b] 3. Provision of moderately and highly effective reversible contraception to women with intellectual and developmental disabilities[c] 4. Receipt of family planning services[d]
Survey with convenience sample	1. Long-acting reversible and permanent contraception—awareness of, interest in, and experience with developmental disability[e] 2. Menstrual concerns and Angelman syndrome[f] 3. Menstrual concerns and autism[g] 4. Menstrual concerns and Rett syndrome[h] 5. Physician comfort, perceived barriers gynecological care for adolescents with disability[i]
Case study	1. Autism and premenstrual mood variation[j] 2. Menstrual concerns and developmental disability[k] 3. Medically necessary sterilization[l]
Qualitative study	1. Physician attitudes and self-report of confidence with disability population[m]
Public health surveillance	1. Contraceptive use at last intercourse[n] 2. Female sterilization and cognitive disability[o] 3. Contraceptive use by disability status[p]
Retrospective cohort study	1. Prenatal care by maternal disability[q]
Retrospective review of electronic medical records with convenience sample	1. Gynecological concerns of adolescents with developmental disabilities[r] 2. Menstrual suppression with the levonorgestrel intrauterine system in girls with developmental delay[s]

Total number of studies used in review ($n = 19$)

[a] Watson et al. [54]

[b] Rurangirwa et al. [26]

[c] Wu et al. [56]

[d] Mosher et al. [24]

[e] Grindlay et al. [57]

[f] Kaskowitz et al. [51]

[g] Hamilton et al. [49]

[h] Hamilton et al. [48]

[i] Shah et al. [78]

[j] Vijapura et al. [50]

[k] Quint et al. [42]

[l] Sowa et al. [66]

[m] Wilkinson et al. [79]

[n] Haynes et al. [61]

[o] Li et al. [60]

[p] Mosher et al. [58]

[q] Horner-Johnson et al. [25]

[r] Burke et al. [36]

[s] Hillard [45]

Table 2

Topics covered by clinical reports, commentary, and reviews included in review of literature

Topic	Population of interest	Authors	Year published
Barriers to care and contraception issues	Women with disabilities	Kaplan	2006
Barriers to sexuality	Individuals with intellectual and developmental disabilities	Sinclair J, Unruh D, Lindstrom L, Scanlon D	2015
Clinical challenges in reproductive health	Adolescents with special needs	Quint EH	2016
Clinical evidence and use of LNG-IUS	Adolescents with special needs	Bayer LL, Hillard PJ	2013
Contraceptive knowledge and use	Women with intellectual, physical, or sensory disabilities	Horner-Johnson W, Moe EL, Stoner RC, Klein KA, Edelman AB, Eden KB, Andresen EM, Caughey AB, Guise JM	2018
Ethical and legal issues in medical decisions; women's health	Women with intellectual disabilities	Wilkinson JE, Cerreto MC	2008
Ethical, legal, and historical analysis of sterilization practices	Women with intellectual disabilities	Begun H	2007
Gynecologic care	Adolescents with special health care needs	Owens K, Honebrink A	1999
Gynecological concerns	Adolescents with physical and developmental disabilities	Quint EH	2014
Health conditions and care considerations	Adults with Down syndrome	Ross WT, Olsen M	2014
Menstrual control	Adolescents with developmental disabilities	Amesse, Bocyce, Pfaff-Amesse	2006
Menstrual issues	Adolescents with developmental disabilities	Quint EH	2008
Menstrual management ethical, legal, medical review	Adolescents with intellectual disabilities	Paransky OI, Zurawin RK	2003
Menstrual suppression	Adolescents	Altshuler AL, Hillard PJ	2014
Reproductive health interventions	Female adolescents with neurodevelopmental disabilities	Fouquier KF, Camune BD	2015
Reproductive health and primary care	Women with intellectual disabilities	Greenwood NW, Wilkinson J	2013
Reproductive health and primary care	Adolescents and young adults with intellectual and developmental disabilities	Walters FP, Gray SH	2018
Sexual health disparities	Young adults with developmental disabilities	Deschaine M	2011
Sexual health education	Adolescents with developmental disabilities	Tice CJ, Hall DMH	2008
Sexual health education	Individuals with developmental disabilities	Travers J, Tincani M, Whitby PS, Boutot EA	2014
Sexuality and disability	Youth and women in foster care with intellectual and developmental disabilities	Ballan MS, Freyer MB	2017
Sexuality and disability	Individuals with physical and developmental disabilities	Di Guilio G	2003
Sexuality and disability	Adolescents with disability	Holland-Hall C, Quint EH	2017
Sexuality and disability	Individuals with developmental disabilities	Milligan MS, Neufeldt AH	2001

Topic	Population of interest	Authors	Year published
Sexuality and disability	Children and adolescents with developmental disabilities	Murphy NA, Elias ER	2006
Sexuality issues and gynecologic care	Adolescents with developmental disabilities	Greydanus DE, Omar HA	2008
Reproductive justice, contraception, and disability	Women with intellectual and developmental disabilities	Hillard	2018
Reproductive justice, contraception, and disability	Individuals with disability	Wu J, Braunschweig Y, Harris LH, Horner-Johnson W, Ernst SD, Stevens B	2019

LNG-IUS Levonorgestrel intrauterine system

Table 3

Overview of reported disability-related concerns with specific contraceptive methods for adolescent and adult women with intellectual and developmental disabilities

Contraceptive method	**Identified areas of concern**
Oral contraceptives (OCPs)	Challenges with maintenance of prescribed course[a,h] Risk for venous thromboembolism[c] Possible interference with enzyme inducing antiepileptic drugs[d,e]
Depomedroxyprogesterone acetate (DMPA)	Regular office visits for injection[b] Risk of bone density loss and fracture with long-term use[b,i] Risk for excessive weight gain[a,c]
Long-Acting Reversible Contraception (LARC) including levonorgestrel intrauterine device (LNG-IUD) and progesterone implant	Sedation may be required[h] Possible interference with enzyme inducing antiepileptic drugs[d,e] Challenge with nonverbal patients reporting pain/discomfort[a] Bleeding irregularities[c]
Transdermal contraceptive patch	Concerns about self-removal[b,j] Possible interaction with enzyme inducing antiepileptic drugs[g] Risk for venous thromboembolism with long-term use[a]
Sterilization	Consent[h,l] Ethical considerations[d,g,k] Legal restrictions[f,g]

[a] Altshuler and Hillard [53]

[b] Amesse et al. [35]

[c] Fouquier et al. [37]

[d] Kaplan [32]

[e] Owens and Honebrink [46]

[f] Paransky and Zurawin [38]

[g] Quint [39]

[h] Quint [41]

[i] Watson et al. [54]

[j] Holland-Hall and Quint [43]

[k] Walters and Gray [73]

[l] Wilkinson et al. [79]