Research

Sexual Health and Parenting Supports for People with Intellectual and Developmental Disabilities

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Carli Friedman, PhD
CQL | The Council on Quality and Leadership
100 West Road, Suite 300
Towson, MD, 21204
cfriedman@thecouncil.org

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Abstract

Introduction. Historically, people with intellectual and developmental disabilities (IDD) have lacked supports when it comes to sexual health and parenting. The aim of this study was to examine if, and how, Medicaid Home- and Community-Based Services (HCBS) 1915(c) waivers provided sexual health and parenting supports to people with IDD.
Methods. We analyzed 107 fiscal year (FY) 2021 HCBS waivers for people with IDD from across the United States to examine trends in service provision. These data were collected between December 2021 and January 2022.
Results. Approximately 10% of HCBS waivers provided sexual health services to people with IDD and 8% provided parenting services for people with IDD. Most sexual health services took a reactive, sex-negative approach to people with IDD's sexuality, rather than a proactive sex-positive approach. In terms of spending, $282,492 was projected for stand-alone sexual health services and $475,213 for stand-alone parenting services. However, less than 0.05% of people with IDD who received HCBS in FY 2021 were projected to receive stand-alone sexual health or parenting services via the waiver.
Conclusions. HCBS are a useful vehicle to expand sexual health and parenting supports for people with IDD; however, most states have failed to utilize this funding mechanism to promote the sexual and reproductive rights of people with IDD.
Policy Implications. There should be an expansion of sexual health and parenting supports offered to people with IDD in HCBS.

Keywords: People with intellectual and developmental disabilities (IDD); sexual health; parenting; reproduction; Medicaid Home and Community Based Services (HCBS); community living; ableism

People with intellectual and developmental disabilities (IDD) desire intimacy and are capable of sexual and romantic relationships (Bathje et al., 2021; Hole et al., 2021). Yet, people with IDD's sexuality is often viewed through a lens of deviance. People with IDD are frequently desexualized and believed to be not interested or capable of sexual or romantic relationships (Carter et al., 2022; Chin, 2018; Hole et al., 2021). While women with IDD are often portrayed as vulnerable victims, men with IDD are frequently stereotyped as potential predators and offenders (McCarthy, 2014).

As a result of these prejudicial assumptions, people with IDD are infantilized, treated with paternalism, and overprotected; when sex and relationships are discussed, the discourse is often restrictive or punitive (Campbell et al., 2020; Chin, 2018; Grace et al., 2020). This reactive and sex-negative view of people with IDD's sexuality – the focus on violence, abuse, victimization, stigmatization, and control – has at best resulted people with IDD receiving little to no education about sexuality and reproduction and/or having their opportunities for sexual expression taken away, and at worst, contributes to eugenic practices (Bathje et al., 2021; Carter et al., 2022; Hole et al., 2021; McConnell & Phelan, 2022). In fact, there is a long history linking IDD and oppressive sexual and reproductive health practices in the United States. During institutionalization in the 19th century, people with IDD (then defined as "feebleminded") were portrayed as sexually promiscuous, resulting in eugenics practices of sex-segregated institutions, forced sterilization, and a removal of marriage rights (Chin, 2018; McConnell & Phelan, 2022; National Council on Disability, 2012; Powell, 2016; Powell et al., 2020).

Today, ableist perception of people with IDD continue to drive laws and policies around sexuality and reproduction (Chin, 2018; McConnell & Phelan, 2022). For example, despite people with IDD wanting and needing education about sex health, most people with IDD do not

receive sexual education in school or as adults due to perceptions that they need to be protected, they are asexual and therefore do not need sex education, and that they lack capacity to consent (Azzopardi-Lane, 2021; Campbell et al., 2020; Friedman et al., 2014; King et al., 2018; Löfgren-Mårtenson, 2012; Moras, 2015; Strnadová et al., 2022). When sexual education is provided to people with IDD the focus is often narrow, such as about biology, inappropriate sexual behaviors, or abuse, rather than comprehensive education that recognizes people with IDD as sexual beings (Azzopardi-Lane, 2021; Campbell et al., 2020; Löfgren-Mårtenson, 2012; McDaniels & Fleming, 2016; Schaafsma et al., 2015; Taylor & Abernathy, 2022). Yet, proper sex education has the ability to not only expand people with IDD's knowledge and skills, which people with IDD have expressed wanting and needing, but also empower them to make informed choices (Friedman et al., 2014; Phasha & Runo, 2017).

In addition, many states still prohibit people with IDD from marrying, the Supreme Court case legalizing forced sterilization of people with disabilities, *Buck v Bell*, has yet to be overturned, and people with IDD are still coerced to undergo sterilization and abortion (Chin, 2018; McConnell & Phelan, 2022; National Council on Disability, 2012; Powell, 2016; Powell et al., 2020). In addition, although many people with IDD want to be parents and people with IDD can be good parents, in the majority of states, IDD itself is considered grounds for removal of children and termination of parents with IDD's rights (Carter et al., 2022; LaLiberte et al., 2017; National Council on Disability, 2012; Powell, 2016; Powell et al., 2020). In fact, people with IDD are overrepresented in child welfare and more likely to have their cases substantiated and their parental rights removed, with some estimates suggesting removal rates for parents with IDD as high as 40-80% (DeZelar & Lightfoot, 2020; LaLiberte et al., 2017; Lightfoot & DeZelar, 2016; National Council on Disability, 2012; Powell, 2016; Powell et al., 2020). Yet, there are

few services and supports designed to help meet the needs of parents with IDD, such as by helping them learn about parenting skills or helping them with parenting related tasks (DeZelar & Lightfoot, 2019; LaLiberte et al., 2017; National Council on Disability, 2012).

Despite a continued overwhelmingly reactive, sex-negative approach, there is a growing acknowledgement of people with IDD's wants and needs regarding sexuality (Bathje et al., 2021; Carter et al., 2022; Friedman et al., 2014; Moring, 2019). Many have recognized a need to shift toward a proactive, sex-positive approach to people with IDD's sexual and reproductive health (Moring, 2019). In fact, the World Health Organization (2006) notes sexual health

> …is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences… the sexual rights of all persons must be respected, protected and fulfilled. (p. 5)

A sex-positive approach includes comprehensive sex education, focuses on rights, and promotes inclusivity (Moring, 2019; Williams et al., 2013), all of which are much needed for people with IDD as they have asked for more education, opportunities for sexual expression, and the removal of systemic barriers to sex, relationships, and parenthood (Chin, 2018; Friedman et al., 2014; Grace et al., 2020).

While there is a lack of a comprehensive system to support people with IDD when it comes to sexuality and parenting in the United States, as the largest source of Long-Term Services and Supports (LTSS) for people with IDD (Braddock et al., 2017), we believe Medicaid Home- and Community-Based Services (HCBS) 1915(c) waivers could be a fruitful and efficient mechanism to provide sex-positive education and support. Medicaid HCBS waivers allow states to create tailored, community-based service programs for specific populations that would

otherwise require institutionalization. For example, in contrast to acute care services which only provide services for physical and mental health, HCBS for people with IDD offer a wide range of wrap-around services to support community-living and quality of life, including residential supports, employment supports, community integration services, and transportation, among others. HCBS are designed to prevent re/institutionalization, promote health and wellbeing, and help people with IDD live and thrive in their communities, including to the same degree as nondisabled people who do not receive HCBS (Centers for Medicare and Medicaid Services, 2014, 2019). For these reasons, the aim of this study was to examine if, and how, Medicaid HCBS 1915(c) waivers provided sexual health and parenting supports to people with IDD. To do so, we analyzed 107 fiscal year (FY) 2021 HCBS waivers for people with IDD from across the United States.

Methods

Data from this study came from Medicaid HCBS 1915(c) waivers – policy documents where states outline which services and supports they will offer in these programs – which were obtained from Medicaid.gov between December 2021 and January 2022. To be included in data collection, waivers needed to be 1915(c), serve people with IDD (developmental disabilities [DD], intellectual disabilities [ID], and/or autism [ASD]) and include FY 2021. While most states used the state FY (July 1, 2020 to June 30, 2021), others used the federal FY (October 1, 2020 to September 30, 2021), or the 2021 calendar year (January 1, 2021 to December 31, 2021); we used FY for consistency. This process resulted in 107 FY 2021 HCBS 1915(c) waivers for people with IDD from 44 states and the District of Columbia.

The Centers for Medicare and Medicaid Services (CMS) requires states describe the following in their waiver applications: CMS assurances and requirements; levels of care; waiver

administration and operation; participant access and eligibility; participant services; service planning and delivery; participant direction of services; participant rights; participant safeguards; quality improvement strategies; financial accountability; and cost-neutrality demonstrations (Centers for Medicare and Medicaid Services, 2019). We used this information, specifically the 'participant services' section (appendix C), where states detail the services provided in the waiver, to determine which HCBS IDD waivers were providing services related to sexual health and parenting supports in FY 2021. To analyze service definitions of the sexual health and parenting supports for trends and determine if each took a sex-negative approach (i.e., reactive, focus on avoidance, danger, victimization, deviance, control), or sex-positive approach (i.e., proactive, see people with IDD as sexual beings, promote sexual expression and opportunities, emphasis rights and education; Bullough, 1976; Queen & Comella, 2008), we used content analysis (Patton, 2002; Zhang & Wildemuth, 2009). Content analysis, a common form of analysis for text-based data (Hsieh & Shannon, 2005), is described as "qualitative data reduction and sense-making effort that takes a volume of qualitative material and attempts to identify core consistencies and meanings" (Patton, 2002, p. 453). Using this method, we assigned a code to each service definition, while creating an emerging inductive coding scheme using the constant comparison method (Glaser, 1992). When all definitions were coded, we returned to the data to confirm coding consistency and alignment with the coding scheme. Prolonged engagement in the data and continuous critical reflection was used throughout the study to ensure qualitative rigor and credibility (Zhang & Wildemuth, 2009).

Sexual health and parenting services that were specific, stand-alone services, which exclusively provided sexual health or parenting supports, were further quantitatively analyzed for expenditures. (When sexuality or parenting supports were embedded as part of a larger/bulk

service [e.g., habilitation], expenditures could not be differentiated.) Using descriptive statistics, we analyzed service expenditures information from waivers' cost-neutrality demonstrations (Appendix J) to determine projected number of people served, total spending, and reimbursement rates for stand-alone sexual health and parenting services.

Results

Sexual Health Services

In FY 2021, five states and the District of Columbia offered 40 sexual health services through eleven different waivers (10.3% of all waivers; Table 1). The majority of sexual health services (87.5%, *n* = 35) were reactive services, viewing sexuality negatively. Reactive services were most often (82.9%, *n* = 29) provided in the form of behavior support for sexually inappropriate behavior. For example, the definition for Washington Basic Plus waiver's (WA.0409.R03.11) "behavioral health stabilization services - positive behavior support and consultation" included,

> Positive behavior support and consultation includes the development and implementation of programs designed to support waiver participants using… direct interventions with the person to decrease aggressive, destructive, and sexually inappropriate or other behaviors that compromise their ability to remain in the community (i.e., training, specialized cognitive counseling, conducting a functional assessment, development and implementation of a positive behavior support plan).

Other times they included the assessments of sexually inappropriate behavior and the development of behavior plans (22.9%, *n* = 8). For example, Washington Individual and Family Services' (WA.1186.R01.08) "risk assessment" service was described as "professional

evaluations of violent, stalking, sexually violent, predatory and/or opportunistic behavior to determine the need for psychological, medical or therapeutic services."

Among the sexual health services, 12.5% (*n* = 5) were proactive services, taking a positive view of sexuality and providing sexual health education. All five proactive services (100.0%) provided sexuality awareness education; topics of reproduction (80%, *n* = 4), safe sex (80%, *n* = 4), and victimization avoidance (80%, *n* = 4) were also common. For example, District of Columbia People with IDD Waiver's (DC.0307.R04.03) "wellness services - sexual education" described, "Sexuality education that provides training in sexuality awareness, reproduction education, safe sexual practices and victimization avoidance." Two proactive sexual health services (40.0%) also included focus on social skills. For example, the definition for New Mexico's Developmental Disabilities Waiver Program's (NM.0173.R06.01) "socialization and sexuality individual" included:

> The Socialization and Sexuality Education service is intended to provide a proactive educational program about the values and critical thinking skills needed to form and maintain meaningful relationships, and about healthy sexuality and sexual expression. Social skills learning objectives include positive self-image, communication skills, doing things independently and with others, and using paid and natural supports.

Finally, California HCBS Waiver for Californians with Developmental Disabilities' (CA.0336.R04.09; *n* =1, 20.0%) "intensive transition services" included focus on "fostering healthy relationships."

Of the 40 sexual health services provided to people with IDD, 85.0% (*n* = 34) of sexual health services were embedded within another service (e.g., residential habilitation, behavior

supports), while 15.0% (*n* = 6) were specific stand-alone sexual health services. Among stand-alone sexual health services, a total of 352 people with IDD were projected to receive these services in FY 2021; 120 people (34.1%) were projected to receive reactive sexual health services, and 232 (65.9%) proactive sexual health services. A total of $282,492 of spending was projected for stand-alone sexual health services – $147,591 (52.2%) for reactive services, and $134,901 (47.8%) for proactive services. The average total spending for stand-alone sexual health services per participating waiver was $47,082.

An average of $803 of annual spending was projected by person on average, ranging from $224 per person a year (District of Columbia's Individual and Family Support Waiver's [DC.1766.R00.00] "wellness - sexuality education") to $1,558 per person a year (NM.0173.R06.01's "Preliminary Risk Screening and Consultation Related To Inappropriate Sexual Behavior, Standard"). Reactive services projecting to spend more per person on average ($1,230) than proactive services ($581).

In terms of reimbursement rates, NM.0173.R06.01's "socialization and sexuality individual," and "socialization and sexuality classes" reimbursed per 'series,' with a rate of $747.13 and $708.00 per series respectively. People were projected to receive 1.07 'series' on average for the "social and sexuality individual," and 1.17 'series' on average for "socialization and sexuality classes." The remaining stand-alone sexuality services had an average hourly reimbursement rate of $89.85, with the average hourly rate being slightly higher for reactive sexual health services ($96.56) than proactive sexual health services ($83.14). Among these four hourly services, people with IDD were projected to receive an average of 9 hours of sexual health services in a year; this amounted to an average of 14 hours of reactive sexual health services and an average of 4 hours of proactive sexual health services.

Parenting Services

Five states and the District of Columbia provided a total of 54 parenting services through their 9 waivers (8.4% of waivers; Table 2). All of the parenting services took a proactive approach, supporting people with IDD to develop parenting skills (100.0%, *n* = 54). For example, Pennsylvania Community Living Waiver's (PA.1486.R00.11) "in-home and community support" service included,

> assistance, support and guidance (prompting, instruction, modeling, reinforcement) will be provided to the participant as needed to enable him or her to… Successfully parent his or her child(ren). This includes assessing parenting competency, as well as modeling and teaching parenting skills such as discipline techniques, child development, health and safety issues and decision-making skills.

Many also provided individualized training about child welfare (27.8%, *n* = 15). For example, Connecticut Individual and Family Support Waiver's (CT.0426.R03.02) "parenting support direct hire per 15 minutes" service was described as "Parenting Support assists eligible consumers [people with IDD] who are or will be parents in developing appropriate parenting skills… Parents will receive training that is individualized and focused on the health and welfare and developmental needs of their child." In addition, WA.1186.R01.08's "supported parenting" also included education specifically about "areas critical to parenting, including child development, nutrition and health, safety, childcare, money management, time and household management and housing."

Of those services that specified (*n* = 13), parenting services could be provided for expectant parents (*n* = 13) as well as current parents with custody of their children (*n* = 13). Nine

services allowed parenting services to be provided to parents who had visitation rights with their children, and three services prohibited parenting services to be received by parents with visitation rights. Eight services allowed parenting services to be provided to parents who were pursing reunification, one service allowed parents pursing reunification to receive these services only in a group format rather than individualized, and three services prohibited parents pursing reunification from receiving these services.

Of the 54 parenting services provided to people with IDD, 24.1% (*n* = 13) were stand-alone services, and 75.9% (*n* = 41) were embedded services. A total of 52 people with IDD were projected to receive stand-alone parenting services. A total of $476,213 of spending was projected for stand-alone parenting services. Stand-alone parenting services projected an average total spending of $36,632, ranging from $5.34 (DC.1766.R00.00's "parenting supports - professional small group [1:4]," "parenting supports - peer individual [1:1]," "parenting supports - peer small group [1:2]," "parenting supports - peer small group [1:3]," and "parenting supports - peer small group [1:4]") to $231,472 (Connecticut's Comprehensive Supports Waiver's [CT.0437.R03.01] "parenting support").

An average of $9,158 of spending was projected per person a year for parenting services. Average spending per person ranged from $5.34 for DC.1766.R00.00's "parenting supports - professional small group [1:4]," "parenting supports - peer individual [1:1]," "parenting supports - peer small group [1:2]," "parenting supports - peer small group [1:3]," and "parenting supports - peer small group [1:4]," to $14,269 for (CT.0426.R03.02's "parenting support direct hire per 15 minutes" and "parenting support agency per 15 minutes" services.

The average hourly reimbursement rate for stand-alone parenting services was $41.40. Average hourly reimbursement rate ranged from $10.68 an hour (DC.1766.R00.00's "parenting

supports - professional small group [1:4],” “parenting supports - peer individual [1:1],” “parenting supports - peer small group [1:2],” “parenting supports - peer small group [1:3],” and “parenting supports - peer small group [1:4]”) to $82.78 per hour (WA.1186.R01.08’s “supported parenting”). On average, people with IDD were projected to receive 59 hours of parenting services in a year, ranging from half an hour for each of DC.1766.R00.00’s parenting services to 200 hours for CT.0426.R03.02’s “parenting support direct hire per 15 minutes” and “parenting support agency per 15 minutes,” and CT.0437.R03.01’s “parenting support” services.

Discussion

Although many people with IDD are interested in sex and parenting, attitudes about sex, parenting, and IDD predominantly manifest in the form of shame, stigma, and bias, resulting in paternalism and oppression (Bathje et al., 2021; DeZelar & Lightfoot, 2020; Powell, 2016; Powell et al., 2020; Strnadová et al., 2017). The aim of this study was to examine if, and, how, states provided sexual health and parenting services to people with IDD in their HCBS waivers. In FY 2021, states provided 40 sexual health services and 54 parenting support services to people with IDD in HCBS. More than three-quarters of a million dollars was projected for stand-alone sexual health ($282,492) and parenting services ($475,213); however, stand-alone sexual health services comprised only 0.007% of total FY 2021 spending for people with IDD, and parenting services only 0.001%. In fact, less than 0.05% of people with IDD who received HCBS were projected to receive stand-alone sexual health (0.04%) and parenting services (0.006%) via a waiver.

While many people with IDD have a lack of knowledge about sexual health, people with IDD would like more education about sexual health (Carter et al., 2022; Friedman et al., 2014; Hole et al., 2021; McConnell & Phelan, 2022). In fact, people with IDD in Hole et al.’s (2021)

study specifically wanted sex education to also be offered after high school – on an ongoing basis – such as reflected in those HCBS waivers that offered these services in this study. As such, we believe it would be beneficial to expand sexual health services in HCBS.

In addition, more sexual health services were reactive, viewing sexuality negatively and focusing on problem behaviors, than proactive, taking a positive, healthy approach to sexual heath, including by promoting sex education. Moreover, for stand-alone sexual health services in particular, more funding was allocated towards reactive services overall, more money was projected per person for reactive services, reactive services were paid at a higher hourly reimbursement rate, and people received more hours of reactive services a year. While reactive services can be important to help reduce and prevent sexually inappropriate and/or dangerous behavior, the lack of attention to proactive sexual health services which promote healthy relationships and communication not only represents a missed opportunity to improve the quality of life of people with IDD, it also reinforces the idea that people with IDD's sexuality is deviant. In fact, additional emphasis on proactive services in HCBS, including an expansion of sexual education of people with IDD, could help reduce the need for some reactive sexual health services (Williams et al., 2013).

Parenting Services and Supports

Only a fraction of IDD HCBS waivers (8.4%) provided parenting services in FY2021 and only 52 people with IDD out of the 861,038 who received HCBS in FY 2021 (Friedman, 2022) were projected to receive stand-alone parenting services. While this small amount may reflect that offering these types of services, especially in HCBS, is a relatively new trend (which will hopefully grow in the future), this limited service provision could be because of assumptions that people with IDD are not interested in or capable of being parents. However, we believe

providing parenting supports in HCBS represents a novel approach to not only supporting people with IDD's rights to be parents, but also to help reduce the number of people with IDD who have their children removed; as such, we believe parenting services for people with IDD should be expanded in HCBS. HCBS may be an especially pertinent mechanism for supporting parents with IDD as mothers with IDD are significantly more likely to receive Medicaid than mothers without IDD (Powell et al., 2017).

Parenting supports are not often provided for people with IDD (National Council on Disability, 2012); yet, with assistance and education people with IDD can learn skills to parent and create safe and nurturing environments for their children (McConnell & Phelan, 2022; Powell, 2016). While not all people with IDD need parenting supports to be great parents, as parenthood is one of people with IDD's rights, people with IDD should have access to parenting supports in HCBS, if they want or need them. Given the preferences of people with IDD, these programs should be implemented in ways that are family-centered and "harness their strengths and preferences and promote collaborative decision making" (Collings et al., 2017, p. 498).

Even among those waivers that provided parenting supports, a number of parenting services prohibited parents with IDD without custody of their children to participate in these services. We believe this is a missed opportunity since parenting supports may help people with IDD with reunification and/or the expansion of visitation rights. In fact, Powell (2016) notes "child welfare agencies and courts also often presume [parents with IDD] are unable to benefit from family preservation and reunification supports and services. In other words, there is a belief that parents with intellectual disabilities are unable to learn the necessary skills to safely parent" (p. 143).

In addition to increasing availability and depth of parenting supports, supplementing other areas of HCBS provision would also help support parents with IDD and prevent loss of custody and/or rights (National Council on Disability, 2012). In fact, a range of formal supports can help parents with IDD cope (Collings et al., 2017). For example, the National Council on Disability (National Council on Disability, 2012) recommends CMS expand the definition of activities of daily living (ADL) so that personal assistants can be reimbursed for helping people with disabilities with parenting tasks. As parents with IDD are often isolated, an expansion of peer services and supports in HCBS, which were sparsely funded in FY 2021, would be helpful (Friedman, 2022; LaLiberte et al., 2017; National Council on Disability, 2012). Expanding HCBS to include childcare would also be beneficial for parents with IDD. As parents with IDD are more likely to live in poverty than parents without IDD (LaLiberte et al., 2017; Powell, 2016; Powell et al., 2017; Powell et al., 2020), and because Medicaid requires people with IDD to live in poverty to qualify for services, poverty reduction strategies would also help parents with IDD. In fact, disability rights advocates are currently leading an effort to increase benefit and asset limits in Supplemental Security Income to reduce poverty among people with disabilities (Astor, 2021; Vallas & Cortland, 2021).

Ableism: A Key Component that Must be Remedied

While supporting people with IDD to develop parenting skills and providing more opportunities for sex education is beneficial, doing so will not reduce or remove ableist perceptions about people with IDD's interest in sex, ability to parent, and structures that result in many people with IDD's children being taken away simply because they have IDD (LaLiberte et al., 2017; Powell, 2016). To promote the parenting and sexual health rights of people with IDD, discriminatory practices, biases, and ableist perceptions of people with IDD, all of which drive

discriminatory laws, policies, and practices around sexual and reproductive health, must be reduced (Bathje et al., 2021; Chin, 2018; DeZelar & Lightfoot, 2020; Hole et al., 2021; McConnell & Phelan, 2022; Powell, 2016; Powell et al., 2020; Strnadová et al., 2017). Moras (2015) notes "ableist protectionism [is] an individualized reaction to sexual violence," instead there should be a "transformation of structural oppression that perpetuates vulnerability" (p. ix).

Given the anti-discrimination intent of the Americans with Disabilities Act (ADA), it should be leveraged to promote the rights of people with IDD. For example, Chin (2018) argues that the sexual isolation of group homes for people with IDD is discriminatory according to the *Olmstead v. L.C.* decision's integration mandate, which is based on the ADA; as such, Chin (2018) purports sexual rights should be considered part of community integration supports. Furthermore, evidence also suggests the reasonable accommodations people with disabilities are entitled to by the ADA are infrequency provided to parents with disabilities during interactions with child welfare services or appeals court (Lightfoot et al., 2017; Powell et al., 2020).

Moreover, honoring people with IDD's sexual and reproductive rights, requires both taking a more wholistic, comprehensive, sex-positive view of the sexuality of people with IDD (Moring, 2019), and also eradicating deficit-based understandings of IDD that portray them as incompetent, child-like, and low ability, resulting in paternalism, rights restrictions, and oppression (Caldwell, 2011; Carey, 2003). The impact of which is likely intensified further for people with IDD who face additional forms of prejudice and oppression, in addition to ableism. For example, parental disability is more likely to be considered in removal determinations for Black and Asian children of parents with disabilities than White children with parents with disabilities (DeZelar & Lightfoot, 2018). In fact, proactive, positive approaches to people with

IDD's sexuality and reproduction may be especially beneficial for people with IDD who are multiply marginalized (Moring, 2019; Williams et al., 2013).

People with IDD's parents also play an important role in sexuality and ableism. Not only are the attitudes of people with IDD's parents towards their sexual health a predictor of people with IDD's sexual and emotional functioning, many family members of people with IDD view people with IDD's sexuality as deviant (Haynes, 2016; Retznik et al., 2022; Swango-Wilson, 2008). Many also infantilize people with IDD and do not think of them as sexual beings (Bates et al., 2021; Pownall et al., 2012; Retznik et al., 2022; Swango-Wilson, 2008; Taylor & Abernathy, 2022). As a result, and because of concerns of abuse and fears that teaching their children with IDD about sexuality will encourage sexual behavior, many family members do not discuss sex with their children with IDD, even as adults, and may even serve as gatekeepers to sexual education, sexuality, and intimate relationships (Foley, 2013; Pownall et al., 2012; Retznik et al., 2022; Schaafsma et al., 2015; Taylor & Abernathy, 2022). Conversely, when family members have a positive view of people with IDD's sexuality and are more open minded, people with IDD are less likely to internalize sexual ableism, having more agency and less stigma (Campbell et al., 2020; Retznik et al., 2022).

Limitations

When interpreting the findings from this study, a number of limitations should be noted. As embedded sexual health and parenting services were incorporated into bulk/larger services, we were not able to differentiate expenditures for the aspects of those services that related to sexual health and/or parenting from other components of those services. As such, our examination of allocation and expenditures was limited to stand-alone sexual health and parenting services. In addition, it is important to note that Medicaid HCBS 1915(c) waivers are

states' projections made to the federal government – they are not utilization data. However, they are an accurate proxy because they are based on previous years' utilization; previous research has also found waiver projections to be similar to utilization data (Rizzolo et al., 2013). Finally, this study examined if, and, how, states provided sexual health and parenting services; there was no way to examine the quality of these services. Future research should compare the quality of HCBS sexual health and parenting services, including to determine the impact on people with IDD's outcomes.

Conclusions

According to CMS (2019), HCBS waivers' "design must provide for continuously and effectively assuring the health and welfare of waiver participants" (p. 8). By providing sexual health and parenting services to people with IDD in HCBS waivers, states have the opportunity to do exactly that. While we are encouraged by the states which are currently utilizing HCBS waivers to provide sexual health and parenting supports to people with IDD, as of FY 2021, only a fraction of states were doing so. Moreover, the approach to sexual health services in HCBS is still predominantly reactive, taking a sex-negative approach. Expanding sexual health and parenting supports in HCBS is needed to not only meet the aims of HCBS, but also to honor the sexual health and reproductive rights of people with IDD.

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Table 1
Sexual Health Services for People with IDD

State	Waiver	Service	Reactive (R) or proactive (P)	Stand-alone (S) or embedded (E)	Allocation projections for stand-alone services				
					People	Total spending	Average spending per person	Average reimbursement rate	Average annual units per person
California	CA.0336.R04.09	Intensive transition services	P	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0305.R05.11	Community connector	R	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0305.R05.11	Habilitation - foster home level 1	R	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0305.R05.11	Habilitation - foster home level 2	R	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0305.R05.11	Habilitation - foster home level 3	R	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0305.R05.11	Habilitation - foster home level 4	R	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0305.R05.11	Habilitation - foster home level 5	R	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0305.R05.11	Habilitation - foster home level 6	R	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0305.R05.11	Habilitation - group home level 1	R	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0305.R05.11	Habilitation - group home level 2	R	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0305.R05.11	Habilitation - group home level 3	R	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0305.R05.11	Habilitation - group home level 4	R	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0305.R05.11	Habilitation - group home level 5	R	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0305.R05.11	Habilitation - group home level 6	R	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0305.R05.11	Habilitation - residential child care facility level 1	R	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0305.R05.11	Habilitation - residential child care facility level 2	R	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0305.R05.11	Habilitation - residential child care facility level 3	R	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0305.R05.11	Habilitation - residential child care facility level 4	R	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0305.R05.11	Habilitation - residential child care facility level 5	R	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0305.R05.11	Habilitation - residential child care facility level 6	R	E	n/a	n/a	n/a	n/a	n/a
District of Columbia	DC.0307.R04.03	Wellness services - sexual education	P	S	4	$897.56	$224.39	$82.16/hour	5.63 hours
District of Columbia	DC.1766.R00.00	Wellness - sexuality education	P	S	1	$33.00	$33.00	$84.12/hour	2.67 hours

New Mexico	NM.0173.R06.01	Preliminary risk screening and consultation related to inappropriate sexual behavior, standard	R	S	6	$9,348.83	$1,558.14	$108.60/hour	14.35 hours
New Mexico	NM.0173.R06.01	Preliminary risk screening and consultation related to inappropriate sexual behavior, Incentive	R	S	114	$138,242.18	$1,212.65	$84.52/hour	14.35 hours
New Mexico	NM.0173.R06.01	Socialization and sexuality individual	P	S	24	$19,186.30	$799.43	$747.13/series	1.07 series
New Mexico	NM.0173.R06.01	Socialization and sexuality classes	P	S	56	$46,388.16	$828.36	$708.00/series	1.17 series
Pennsylvania	PA.0147.R06.11	Behavioral support	R	E	n/a	n/a	n/a	n/a	n/a
Pennsylvania	PA.1486.R00.11	Behavioral support	R	E	n/a	n/a	n/a	n/a	n/a
Washington	WA.0409.R03.11	Behavioral health stabilization services - positive behavior support and consultation	R	E	n/a	n/a	n/a	n/a	n/a
Washington	WA.0409.R03.11	Positive behavior support and consultation	R	E	n/a	n/a	n/a	n/a	n/a
Washington	WA.0409.R03.11	Risk assessment	R	E	n/a	n/a	n/a	n/a	n/a
Washington	WA.0410.R03.13	Behavioral health stabilization services - positive behavior support and consultation	R	E	n/a	n/a	n/a	n/a	n/a
Washington	WA.0410.R03.13	Positive behavior support and consultation	R	E	n/a	n/a	n/a	n/a	n/a
Washington	WA.0410.R03.13	Risk assessment	R	E	n/a	n/a	n/a	n/a	n/a
Washington	WA.0411.R03.12	Behavioral health stabilization services - positive behavior support and consultation	R	E	n/a	n/a	n/a	n/a	n/a
Washington	WA.0411.R03.12	Positive behavior support and consultation	R	E	n/a	n/a	n/a	n/a	n/a
Washington	WA.0411.R03.12	Risk assessment	R	E	n/a	n/a	n/a	n/a	n/a
Washington	WA.1186.R01.08	Behavioral health stabilization services - positive behavior support and consultation	R	E	n/a	n/a	n/a	n/a	n/a
Washington	WA.1186.R01.08	Positive behavior support and consultation	R	E	n/a	n/a	n/a	n/a	n/a
Washington	WA.1186.R01.08	Risk assessment	R	E	n/a	n/a	n/a	n/a	n/a

Table 2
Parenting Services for People with IDD

State	Waiver	Service	Stand-alone (S) or embedded (E)	Allocation projections for stand-alone services				
				People	Total spending	Average spending per person	Average reimbursement rate	Average annual units per person
Colorado	CO.0007.R08.11	Group residential services and supports - level 1	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0007.R08.11	Group residential services and supports - level 2	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0007.R08.11	Group residential services and supports - level 3	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0007.R08.11	Group residential services and supports - level 4	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0007.R08.11	Group residential services and supports - level 5	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0007.R08.11	Group residential services and supports - level 6	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0007.R08.11	Group residential services and supports - level 7	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0007.R08.11	Individual residential services and supports - level 1	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0007.R08.11	Individual residential services and supports - level 2	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0007.R08.11	Individual residential services and supports - level 3	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0007.R08.11	Individual residential services and supports - level 4	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0007.R08.11	Individual residential services and supports - level 5	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0007.R08.11	Individual residential services and supports - level 6	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0007.R08.11	Individual residential services and supports - level 7	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0007.R08.11	Individual residential services and supports/host home - level 1	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0007.R08.11	Individual residential services and supports/host home - level 2	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0007.R08.11	Individual residential services and supports/host home - level 3	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0007.R08.11	Individual residential services and supports/host home - level 4	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0007.R08.11	Individual residential services and supports/host home - level 5	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0007.R08.11	Individual residential services and supports/host home - level 6	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0007.R08.11	Individual residential services and supports/host home - level 7	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0305.R05.11	Habilitation - foster home level 1	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0305.R05.11	Habilitation - foster home level 2	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0305.R05.11	Habilitation - foster home level 3	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0305.R05.11	Habilitation - foster home level 4	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0305.R05.11	Habilitation - foster home level 5	E	n/a	n/a	n/a	n/a	n/a

Colorado	CO.0305.R05.11	Habilitation - foster home level 6	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0305.R05.11	Habilitation - group home level 1	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0305.R05.11	Habilitation - group home level 2	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0305.R05.11	Habilitation - group home level 3	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0305.R05.11	Habilitation - group home level 4	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0305.R05.11	Habilitation - group home level 5	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0305.R05.11	Habilitation - group home level 6	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0305.R05.11	Habilitation - residential child care facility level 1	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0305.R05.11	Habilitation - residential child care facility level 2	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0305.R05.11	Habilitation - residential child care facility level 3	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0305.R05.11	Habilitation - residential child care facility level 4	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0305.R05.11	Habilitation - residential child care facility level 5	E	n/a	n/a	n/a	n/a	n/a
Colorado	CO.0305.R05.11	Habilitation - residential child care facility level 6	E	n/a	n/a	n/a	n/a	n/a
Connecticut	CT.0426.R03.02	Parenting support direct hire per 15 minutes	S	4	$57,184.00	$14,296.00	$71.48/hour	200 hours
Connecticut	CT.0426.R03.02	Parenting support agency per 15 minutes	S	8	$114,368.00	$14,296.00	$71.48/hour	200 hours
Connecticut	CT.0437.R03.01	Parenting support	S	17	$231,472.00	$13,616.00	$68.08/hour	200 hours
District of Columbia	DC.0307.R04.03	Parenting supports - peer small group (1:4)	S	148	$68,428.60	$462.36	$10.68/hour	0.50 hours
District of Columbia	DC.1766.R00.00	Parenting supports - professional individual (1:1)	S	1	$13.32	$13.32	$66.00/hour	0.50 hours
District of Columbia	DC.1766.R00.00	Parenting supports - professional small group (1:2)	S	1	$18.14	$18.14	$26.64/hour	0.50 hours
District of Columbia	DC.1766.R00.00	Parenting supports - professional small group (1:3)	S	1	$5.34	$5.34	$36.28/hour	0.50 hours
District of Columbia	DC.1766.R00.00	Parenting supports - professional small group (1:4)	S	1	$18.14	$18.14	$10.68/hour	0.50 hours
District of Columbia	DC.1766.R00.00	Parenting supports - peer individual (1:1)	S	1	$5.34	$5.34	$36.28/hour	0.50 hours
District of Columbia	DC.1766.R00.00	Parenting supports - peer small group (1:2)	S	1	$5.34	$5.34	$10.68/hour	0.50 hours
District of Columbia	DC.1766.R00.00	Parenting supports - peer small group (1:3)	S	1	$5.34	$5.34	$10.68/hour	0.50 hours
North Dakota	ND.0037.R08.04	Parenting support	S	13	$71,926.40	$5,532.80	$36.40/hour	152 hours
Pennsylvania	PA.0147.R06.11	In-home and community support	E	n/a	n/a	n/a	n/a	n/a
Pennsylvania	PA.1486.R00.11	In-home and community support	E	n/a	n/a	n/a	n/a	n/a
Washington	WA.1186.R01.08	Supported parenting	S	2	$1,158.92	$579.46	$82.78/hour	7 hours

Note. All parenting services were proactive.