

Sexual Rights

of Adults with Developmental Disabilities

**Bibliography of Academic
and Professional Literature**



publication of
Capacity to Love

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Sexual Rights

of Adults with Developmental Disabilities

Bibliography of Academic and Professional Literature

Preface

As the references cited in this bibliography demonstrate, an interest in the sexual rights of adults with developmental disabilities has steadily grown. The glimmer of interest expressed by some pioneers on this issue in the past has now become a topic of mainstream conversation.

Last year, the Missouri Developmental Disabilities Council (MODDC) demonstrated its interest by offering a three-year \$150,000 [grant](#) to fund a sexuality education project for people with developmental disabilities.

The three-year project will provide comprehensive sexuality education to self-advocates and advocates. The grantee for this project will engage with a nationally recognized curriculum to provide trainings and train self-advocates and advocates as trainers on this topic. The curriculum will be selected by the grantee and approved by MODDC.

The Council stated that it considers “comprehensive” to mean that this education should be inclusive of, but not limited to, the physical and biological aspects of human sexuality. A comprehensive sexuality education curriculum will educate about body autonomy, sexual self-advocacy and healthy relationships. The comprehensive curriculum should explore the intersectionality of sexuality and employment, healthy relationships, advocacy, unnecessary legal actions and other aspects of a self-advocate’s life.

The Alternatives to Guardianship Project agrees with MODDC on the importance of sex education for self-advocates. However, this is just the first of many steps that need to be taken to protect sexual rights. Sexuality must be addressed responsibly by health care professionals, adult protective service workers, teachers and school administrators, the judiciary, the legal profession, capacity assessment professionals, disability service providers, disability rights advocates, and legislators. A comprehensive approach is needed.

This bibliography offers those with a sincere interest in this topic access to a wide range of studies and reports on which to build a new set of policies and protocols that will respect and protect the sexual rights of adults with developmental disabilities in Missouri.

Sexual Rights

Joint Policy Statement of The Arc and AAIDD (2008) [Link](#)

Abstract: The policy statement affirms that: people with intellectual disabilities and developmental disabilities (IDD), like all people, have inherent sexual rights. These rights and needs must be affirmed, defended, and respected; and that every person has the right to exercise choices regarding sexual expression and social relationships. The presence of IDD, regardless of severity, does not, in itself, justify loss of rights related to sexuality.

Policy Statement of TASH (2000) [Link](#)

Abstract: The policy statement affirms: the right for all people with disabilities to make individual choices in all areas of human sexuality; the right to private sexual conduct, the right to family planning decisions and the right to express a sexual identity/orientation; and that all people, including people with disabilities, should have the freedom and opportunity to express their sexuality, establish relationships and marry or co-habitate if they so choose.

Sexual Rights Statement, Illinois Guardianship and Advocacy Commission, Department of Human Services - [Link](#)

Abstract: The policy statement affirms: persons with disabilities have the right to: explore and define one's own sexuality, sexual orientation, gender identity and sexual expression without judgement or discrimination; decide whether and when to be sexually active; choose one's own sexual partners and have privacy and dignity related to dating and sexual intimacy; have safe and pleasurable sexual experiences.

Sexual Rights and Advocacy, SCARC (2019) [Link](#)

Abstract: This policy statement was developed by SCARC, a nonprofit organization helping individuals with developmental disabilities and their families in Sussex County, New Jersey. The purpose of the policy is to assure that the inherent sexual rights and basic human needs of persons with intellectual and developmental disabilities are affirmed, defended, and respected, and to protect people with intellectual and developmental disabilities from harm.

“The Right to Sexuality, Reproductive Health, and Found a Family for People with Intellectual Disability: A Systematic Review,” International Journal of Environmental Research and Public Health (January 2023) [Link](#)

Abstract: Although sexuality, reproductive health, and starting a family are human rights that should be guaranteed for all citizens, they are still taboo issues for people with intellectual disability (ID), and even more so for women with ID. This paper systematically reviews the

current qualitative and quantitative evidence on the rights of people with ID in regard to Articles 23 (right to home and family) and 25 (health, specifically sexual and reproductive health) of the Convention on the Rights of Persons with Disabilities (CRPD). A systematic review of the current literature, following PRISMA 2020, was carried out in ERIC, PsychInfo, Scopus, PubMed, ProQuest, and Web of Science. In all, 151 articles were included for review. The studies were categorized into six themes: attitudes, intimate relationships, sexual and reproductive health, sexuality and sex education, pregnancy, and parenthood. There are still many barriers that prevent people with ID from fully exercising their right to sexuality, reproductive health, and parenthood, most notably communicative and attitudinal barriers. These findings underline the need to continue advancing the rights of people with ID, relying on Schalock and Verdurgo's eight-dimensional quality of life model as the ideal conceptual framework for translating such abstract concepts into practice and policy.

“Group Homes as Sex Police and the Role of the Olmstead Integration Mandate,”
N.Y.U. Review of Law & Social Change, Vol. 42, No. 3 (2018) [Link](#)

Abstract:

Adults with intellectual disabilities who live in group homes possess the same complex range of sexual desires and identities as all adults do. However, in group homes throughout the United States, these adults are denied the ability to express their sexuality. This Article addresses the systematic failure of group homes to modify punitive and overprotective policies and to provide services related to sex and intimacy, creating an environment of sexual isolation. Although legal scholars have explored the complexity of disability and sexual consent capacity and examined sexual rights in the context of institutionalized care, they have yet to explore the ramifications of policies and practices within group homes under federal disability rights law. This Article takes on that task and concludes that group homes have an affirmative duty to support intellectually disabled adults in exercising choices around sex and intimacy.

In particular, this Article argues that *Olmstead v. L.C. ex rel. Zimring* and its mandate for community integration under Title II of the Americans with Disabilities Act provides the framework to challenge the sexual isolation of group home residents as disability-based discrimination under the ADA's older integration mandate-sibling, Section 504 of the Rehabilitation Act. Some courts have begun to expand the reach of the integration mandate beyond the physical walls of confinement. It is through this lens that sexual rights can rise from the shadows as an essential aspect of full community integration alongside supports that include employment, education, and skills for daily living. The Article concludes by proposing reasonable modifications that group homes may undertake to avert sexual isolation, striving to balance the sexual rights of residents against the risk of exploitation and abuse that may arise in intimate relationships. A key modification would require group

homes to create or adapt policies and procedures that begin to dismantle the bias, paternalism, and ableism that drives group-home decisions and perpetuates the sexual isolation of adults with intellectual disabilities

“Awareness of Sexual Rights and Empowerment: Quantitative and Qualitative Evaluation of a Sexual Health Intervention for Adults with Intellectual Disability,” *Journal of Sex Research* (Nov.-Dec. 2020) [Link](#)

Abstract: Young people with intellectual disability (ID) rarely have opportunities to form intimate relationships or receive long-term interventions promoting their sexual health and awareness of sexual rights. To promote sexual health in adults with ID in Taiwan, we utilized intervention research and inclusive research to introduce three interventions that involved adults with ID, their parents, and service workers. This paper primarily evaluates the outcomes of a two-year intervention to promote sexual and reproductive health knowledge/positive attitudes and quality of life for adults with ID. A non-equivalent multiple-groups with replications design was used to gather data from 87 adults with ID. In-depth interviews and focus groups were used to collect the experiences and perspectives of adults with ID, service workers and parents. Although the experimental groups did not show a strong quantitative increase in sexual knowledge and sexual attitudes, the qualitative data indicated that the dialogues with and among the participants transformed their perceptions of sexual needs from being sexual problems to being sexual rights, which was empowering for adults with ID. Involving parents and service workers in the intervention and facilitating dialogue between these groups are essential to transform sexual problems of adults with ID into sexual rights.

“The Right to Sexual Relationships,” *Disability Rights Center of New Hampshire, Disability Rapp* (Spring 2020) [Link](#)

Abstract: In a world where we classify, sort, separate, and stigmatize, it is important to remember that people with all types of disabilities are sexual beings, with the same diversity of sexual desires and interests as people without disabilities. It is critical that agencies and service providers promote healthy sexual relationships for the people with disabilities they serve. Service providers must train and support Direct Support Personnel (DSPs) to address sexuality and the sexual needs of the people they support. Sex education and family planning are critical elements of person-centered planning and, yet, they are often omitted. This article makes various recommendations directed to service providers for people with developmental disabilities.

“With Liberty and Justice for All: The Sexual Rights of Adults with Developmental Disabilities (A Focus on California), *Spectrum Institute* (2014) [Link](#)

Abstract:

Preface. Knowledge is power. What people with developmental disabilities need is more knowledge about their sexual rights. With such knowledge they will have the power to exercise those rights in everyday life. While many advances have been made in the areas of education and jobs for people with developmental disabilities, the frontier presenting the greatest challenge today is the area of sexuality and intimate relationships. This report draws upon the author's vast experience in sexual civil liberties advocacy, connecting and using that experience to advance the rights of adults with developmental disabilities – to help them understand their right to experience the same levels of sexual fulfillment and rewarding intimate relationships as everyone else.

Contents. • The Constitution Protects Liberty • Sex: What We Can and Cannot Do • Touching One's Own Body • Sex Videos • Sex Toys • Group Homes • Sex in Public Places • Consenting Adult Activity • Sex Education and Counseling • Duties of Regional Centers • Rights of Conservatees.

Policy Statement of the Association of Regional Center Agencies, ARCA (2002) [Link](#)

Abstract: The policy statement affirms that every individual with a developmental disability has the right to achieve his/her maximum potential on the continuum of social-sexual development. The intent of this policy statement is to incorporate social-sexual related goals and outcomes into the person centered planning process and assist service coordinators with the education and support they will need to help consumers identify their needs on the Individual Program Plan.

Policy Statement of the Florida Developmental Disabilities Council - [Link](#)

Abstract: The policy statement affirms that "All individuals with intellectual/developmental disabilities have the same inalienable rights to life, liberty, and the pursuit of happiness as all other individuals. This includes the right to responsibly engage in interpersonal relationships, which include sexual expressions, where there is mutual consent." (Ames, 1995: 265) Loving relationships, whether they are platonic, familial or romantic, are an important component of a person's physical, emotional and mental well-being. Accordingly, educators and parents need to consider this aspect of life to be a priority in a person's education.

“Assisted Autonomy” and Sexual Rights for Individuals with Down Syndrome,” Thesis at Whitman College (2020) [Link](#)

Abstract: Individuals with Down Syndrome have too often been left out of sexual narratives and misrepresented by societal norms to be antithetical to the autonomous being. By analyzing both the autonomy and rights frameworks in tandem with the experiences of employment and housing opportunities, I argue that “assisted autonomy” increases access

to sexual rights for individuals with Down Syndrome. “Assisted autonomy” refers to one’s ability to make decisions or act with the assistance, but not force, of a support system. In the case of Down Syndrome sexuality, this includes accessible sex education, facilitated consent, and sex surrogacy. This thesis hopes to begin the process of shifting the harmful perceptions of autonomy, sexuality, Down Syndrome, and their inherent connections.

Capacity to Consent

“Capacity to Consent to Sex: Legal Standards & Best Practices for Adult Protective Services,” Spectrum Institute (2020) [Link](#)

Knowing the law on capacity, using best practices for assessments, and complying with mandates of the Americans with Disabilities Act, are essential to effective APS investigations, referrals, and social services.

The legal criteria for capacity to consent to sex vary considerably from state to state. The areas of inquiry during a clinical assessment process must match the legal criteria for capacity. The law is the driving force and foundation for an assessment of capacity. Because criteria vary with each state, there can be no uniform protocol throughout the nation for the types of questions that are asked or the areas of an individual’s knowledge that are probed. An assessment professional must learn the legal criteria in the jurisdiction where the assessment is being done and use those criteria to guide the assessment process.

Inquiries into subjects that are not relevant in a particular state would be unnecessarily intrusive, discriminatory, and probably illegal. For example, in several states an individual does not need to know or understand risks or consequences of various types of sex. Nor is there a requirement for the person to understand proper places for sex to occur. Asking questions about such matters in those states would be a form of discrimination against people with disabilities. In other states, an individual must not only know about consequences but also must understand the moral implications of their behavior. In those states, until the law is changed to remove this consideration, any assessment that does not probe into an understanding moral consequences would be legally deficient.

However, there are areas where uniformity in all states is possible: (1) assessing an individual’s understanding of voluntariness, including the ability to resist pressure and to comply when another person says no; (2) the need for assessment professionals to follow the mandates of the Americans with Disabilities Act in the assessment process; and (3) the use of best practices for interviewing people with disabilities.

This report is intended to help APS professionals gain a better understanding of the complexities of assessing capacity to consent to sex so they can provide a proper balance between respecting the freedom of, and providing protection to, their clients.

“Sexual Consent and Disability,” Disability Law Journal, Vol. 2, No. 1 (2022) [Link](#)

Abstract:

Our nation is engaged in deep debate over sexual consent. But to date the discussion has overlooked sexual consent’s implications for a key demographic: people with mental disabilities, for whom the reported incidence of sexual violence is three times that of the nondisabled population. Even as popular debate overlooks the question of sexual consent for those with disabilities, contemporary legal scholars critique governmental over regulation of this area, arguing that it diminishes the agency and dignity of people with disabilities. Yet in defending their position, these scholars rely on empirical data from over twenty years ago, when disability and sexual assault laws and social norms looked quite different than those of today.

Current scholarly discussions about sexual consent and mental disability suffer from an outdated empirical baseline that masks critical information about the profile and experience of sexual violence. This Article creates a new empirical baseline for modern scholarship on sexual assault and disability. Based on an original survey of all fifty states and jurisprudence from the past twenty years of state sexual assault and rape appeals where the victim has a mental disability, this Article updates and critiques four major claims about sexual consent and disability in the current literature. First, through a review of statutes across the country, it complicates the traditional notion that statutes are unduly vague in their definition of disability, and as a result, either over or under emphasize disability. The author advances a new organizing taxonomy for sexual assault statutes addressing consent for people with mental disabilities.

Second, this data set upends the prevailing claim by legal scholars that courts overemphasize standardized evidence such as intelligence quotient (IQ) or mental age when judging a person’s functional capacity to consent to sex. Instead, this Article shows that courts frequently look at adaptive abilities to augment standardized evidence but, in doing so, overvalue certain kinds of adaptive evidence that have low probative value, to the detriment of persons with mental disabilities. Third, legislators and legal scholars focus on people in large institutional settings in their critiques of over regulation, but this new data shows that people in community-based settings are more often the complainants in rape and sexual assault cases. This raises important questions about the types of relationships the state regulates (formal versus informal care relationships), the location of these relationships (community versus institutional settings), and issues of class that intersect with disability and sexual regulation. By not addressing the right issues and contexts, current law leaves people with mental disabilities simultaneously more susceptible to sexual violence and less empowered to exercise sexual agency. Finally, the Article more deeply examines the traditional assumption that people with disabilities rarely have access to testify by considering a rarely-mentioned risk: whether testimony by people with disabilities skews

capacity determinations because factfinders cannot see beyond the existence of the disability—a phenomenon which the author terms “the aesthetics of disability.” This Article calls upon scholars, courts, and policymakers to consider difficult questions of regulating sexual consent in ways that are consistent with the current profile and experience of sexual violence for people with mental disabilities reflected in this study.

“Capacity to Consent to Sexual Activity Among Those with Developmental Disabilities,” Stanford Intellectual and Developmental Disabilities Law and Policy Project, Stanford Law School (2018) [Link](#)

Abstract: The law surrounding the capacity of people with developmental disabilities to consent to sexual activity is characterized by an inherent tension between a desire to protect these individuals from harm and a fear of inhibiting their autonomy. The purpose of this guide (78 pp.) is to improve the understanding of those with developmental disabilities as to what their sexual rights are, to inform their families as to what the legal standards are that will apply, and finally, to help both parties identify when such standards have been violated in cases of rape or sexual abuse.

“Approaches to Determine and Manage Sexual Consent Abilities for People With Cognitive Disabilities: Systematic Review,” Interactive Journal of Medical Research, Vol. 11 (2022). [Link](#)

Abstract:

Background. This review focused on how sexual consent ability was determined, managed, and enhanced in people with cognitive disabilities, in order to better understand the recurring themes influencing the design and implementation of these approaches. If a person's consensual ability is compromised, owing to cognitive disability, the formal systems involved must establish plans to balance the individual's rights and restrictions on sexual expression. This review identified these plans, focusing on how they promoted the intimacy rights of the individual.

Objective. This study aims to identify approaches that determine sexual consent ability in people with cognitive disabilities, identify the means of managing and enhancing sexual consent ability in people with cognitive disabilities, and note the recurring themes that influence how these approaches and management systems are designed and implemented.

Methods. A systematic literature review was performed using EBSCOhost (Social Gerontology, CINAHL Plus, MEDLINE, and SocINDEX), Embase, PsyInfo, and Scopus to locate reports on terms expanded on sexual consent and cognitive disability.

Results. In all, 47 articles were identified, featuring assessment practices, legal case studies,

and clinical standards for managing sexual consent capacity in people with cognitive disabilities. A total of 8 studies (5/8, 63% qualitative and 3/8, 38% quantitative) were included out of the 47 articles identified. Approaches for determining sexual consent included functional capacity and person-centered, integrated, and contextual approaches. Management of sexual consent ability included education, attitude, and advanced directives and support networks. The recurring themes that influenced these approaches included the 3 legal criteria of consent, American Bar Association and American Psychological Association Model, Lichtenberg and Strzepek Instrument, Ames and Samowitz Instrument, Lyden approach, Mental Capacity Act of 2005, and Vancouver Coastal Health Authority of 2009.

Conclusions. Determining sexual consent takes a holistic approach, with individuals judged in terms of their adaptive abilities, capacities, and human rights. The attitudes of those using this holistic approach need to be balanced; otherwise, the sexual rights of assessed people could be moved either in favor or against them. The ideal outcome, after person-centered considerations of those living with cognitive disabilities includes the people themselves being involved in the process of personalizing these approaches used to facilitate healthy intimate relationships.

“Sexual Self-Determination of Individuals with Intellectual Disabilities-A Possible Philosophical Conceptualization and Resulting Practical Challenges,” *International Journal of Environmental Research and Public Health*, Vol. 19 (2022) [Link](#)

Abstract:

Background. Self-determination is one of the central values of many societies. Self-determination concerns many areas of life, including sexuality. Unfortunately, the sexuality of individuals with intellectual disabilities (IID) is often discriminated against, and even in their everyday care, sexuality is often given too little space, not least because of knowledge deficits of parents and staff. A practicable conceptualization of sexual self-determination is a prerequisite for helping IID to achieve self-determined sexuality. The aim of this paper is to formulate such an applicable conceptualization and to discuss related challenges.

Method. This paper uses Harry Frankfurt's hierarchical conception of desires and the WHO definition of sexuality to develop a suitable understanding of sexual self-determination.

Results. The mentioned concepts offer promising tools to develop a conceptualization of sexual self-determination with high practical applicability.

Discussion. Sexual self-determination involves decision-making processes in relation to the different dimensions of sexuality. IID do need support to come to these decisions. Challenges

that might be involved with such decision processes will be discussed.

“Sexuality and Incapacity,” *Ohio State Law Journal*, Vol. 76 (2015) pp. 1482-1535. [Link](#)

Abstract: Sexual incapacity doctrines are perhaps the most important form of sexual regulation, as they control access to sex by designating who is legally capable of sexual consent. Most states have adopted sexual incapacity tests for adults that focus narrowly on assessing an individual’s cognitive abilities. These tests serve an important protective function for people with temporary cognitive impairments, such as those rendered incapable due to alcohol or drugs. However, this comes at the cost of barring many people with persistent cognitive impairments, such as Down Syndrome or Alzheimer’s Disease, from any sexual activity. This is despite the fact that said individuals often still have sexual desires and are able to engage in sexual decision-making with support from caregiving networks. The central claim of this Article is that sexual incapacity doctrine should grant legal capacity to adults with persistent cognitive impairments if they are embedded in an adequate decision-making support network. In other words, the right to sexual expression should not be withheld due to cognitive impairment alone. To justify this claim, the Article provides a theory of sexual incapacity doctrine that is grounded in the practice of supported decision-making and the normative foundations of sexual capability and relational autonomy. The Article then sets forth a novel test for sexual consent capacity: cognition-plus. This test focuses on gauging the capacity for volition, assessing the mental capacity of the individual to understand the nature and consequences of the sexual decision, and evaluating the adequacy of the decision-making support system using principles of fiduciary law.

“Sexual health, neurodiversity and capacity to consent to sex,” *Tizard Learning Disability Review*, VOL. 18 NO. 2, pp. 88-97 (2013) [Link](#)

Abstract: The purpose of this paper is to clarify: the law on capacity to consent to sex; ethical and legal factors in assessing decision-making capacity of those on the autism (ASD) and neurodiverse (ND) spectrums; and the legal obligations to promote sexual health devolving to local authorities from April 2013. The paper makes proposals to ensure socio-sexual competence by providing appropriate sex and relationship education (SRE). *Findings*. Consent to sex cannot be regarded as informed, autonomous, valid and lawful without socio-sexual competence. Sex and relationships education should be provided to ensure socio-sexual competence in keeping with international conventions and national laws and policies.

“Capacity of adults with intellectual disabilities to consent to sexual relationships,” *Psychological Medicine*, Vol. 34, pp. 1347–1357 (2004). [Link](#)

Abstract: For people with intellectual disabilities there is a difficult balance to be struck between empowering people to claim their sexual rights and protecting them from abuse.

Hypothetically, services should be guided by whether a particular person with intellectual disabilities has the capacity to consent to sexual relationships. However, there has been little agreement on how to define such capacity. This study examines the issue of capacity to consent to sexual relationships using a functional approach. *Findings.* Adults with intellectual disabilities were significantly less knowledgeable about almost all aspects of sex and appeared significantly more vulnerable to abuse, having difficulty at times distinguishing abusive from consenting relationships. Nevertheless, some adults with intellectual disabilities scored highly on all measures, especially if they had relatively high IQs and had had sex education. *Conclusions.* The reasons for the poorer knowledge and increased vulnerability of people with intellectual disabilities are discussed and it is recommended that they should have on-going access to sex education. Implications of the findings for definitions of capacity to consent to sexual relationships are considered.

“Enhancing capacity to make sexuality-related decisions in people with an intellectual disability,” *Journal of Intellectual Disability Research*, Vol. 53 Part 8 (August 2009) [Link](#)

Abstract:

Aim. The aim of the study was to apply an intervention to the area of sexual knowledge in order to determine if capacity to make sexuality-related decisions could be improved.

Method. The study adopted a single subject design using multiple baseline method with four adults with a moderate intellectual disability. The intervention consisted of individually tailored sex education adapted from Living Your Life (Bustard 2003). Treatment was offered to each participant twice weekly for a 10-week period on a one-to-one basis. The Sexual Consent and Education Assessment (SCEA, Kennedy 1993) was used for measurement purposes. The SCEA K-Scale (knowledge) and the S-Scale (safety practices) were administered weekly throughout the baseline, treatment and post-treatment phases of the study. Staff concerns were also assessed using the SCEA Inappropriate Sexual Behaviour Scale.

Results. All four participants improved their decision-making capacity in all targeted areas as measured by improvements in K-Scale and S-Scale scores. Staff concerns were not increased as indicated by results on the Inappropriate Sexual Behaviour Scale. Six-month follow-up data for three of the participants showed maintenance of scores on the S-Scale and some decay in scores on the K-Scale from post-intervention performance.

Conclusion. The results demonstrate that tailored sexuality education can improve capacity to make sexuality-related decisions

“Assessment of Sexual Consent Capacity,” *Sexuality and Disability*, Vol. 25 (2007) pp. 3–20 [Link](#)

Abstract: This article discusses assessment of sexual consent capacity, its ethical and legal mandates, and a rationale for the assessment of capacity to have a sexual relationship. It reports current assessment practices used by the authors as well as a summary of relevant literature. There is a review and discussion of New York laws, National and State court cases, and policies of National and international authorities relevant to sexual relations between persons who have intellectual disabilities. Technical information about a tool for assessing capacity to give consent for sexual relationships is described. A proposed clinical standard for use in assessing the capacity of a person with cognitive impairments to have a sexual relationship is presented.

“Relationships, sexuality and decision-making capacity in people with an intellectual disability,” *Current Opinion in Psychiatry*, Vol. 24 (2011) pp. 398–402 [Link](#)

Abstract:

Purpose of review. The current review attempts to summarize the current status of our knowledge and clinical practice in the complex and challenging area of relationships and sexuality for people with an intellectual disability.

Recent findings. Although there has been an ideological shift within services for people with an intellectual disability towards person-centredness and inclusivity, this change has not manifested in an obvious way at the practice level in the area of relationships and sexual expression. Recent surveys of caregivers and service providers do show a greater awareness of the fact that sexuality is a central part of personal identity, yet generally restrictive or prohibitive attitudes prevail at both individual and organizational levels. These attitudes appear to reflect a fear of possible legal sanction as well as ethical and moral conflicts. The views and experiences of people with an intellectual disability generally confirm this impression that, whereas some small changes have taken place, the prevailing experience is of restriction. Whereas there is now an abundance of sexuality and relationship educational programmes available, they require more rigorous and systematic evaluation both in terms of their effectiveness for enhancing knowledge and, more importantly, for examining the impact of that education on behaviour and capacity to make sexuality-related decisions, which we know to be a fluid ability.

Summary. There is a need for greater education of caregivers and a need for discussion of the complex issues regarding relationships and sexuality at a societal and policy level. The development of self-advocacy in disability services provides a vehicle to operationalize the changing service ideologies in a way that provides greater opportunities for enriching relationship experiences whilst also preventing undue risk of harm. However, successful self-advocacy requires organizational support, and this remains the greatest challenge for service providers.

“Rethinking Sexual Abuse, Questions of Consent, and Intellectual Disability,” *Sexual Research and Social Policy*, Vol. 7 (2010) pp. 201–213 [Link](#)

Abstract: This article explores sexual abuse for individuals with intellectual disabilities using a case of a young woman with an intellectual disability who was sexually abused by her peer mentor. This article deconstructs the complex notions of competence as denying individuals’ legal recognition of their capacity for sexual expression. The potential for sexual abuse is used as a disqualifier that demands compensation to counter the risk. This compensation takes the form of harm reduction and protectionism. Additionally, the article questions the usefulness of pity as a response to cases of sexual abuse. The article argues that pity, as an emotional response, perpetuates unequal power dynamics between the individual who experiences abuse and those who describe, report upon, and support the individual. Most damaging perhaps is that, when individuals with intellectual disabilities, women especially, are seen as being vulnerable or at risk for sexual abuse, the perceived vulnerability acts as a mechanism to deny their sexual desire.

“The Notion of Consent to Sexual Activity for Persons with Mental Disabilities,” *Liverpool Law Review*, Vol. 31 (2010) pp. 111–135 [Link](#)

Abstract: This paper seeks to examine the notion of consent to sexual activity as it is applied to situations involving persons with mental disabilities both by both medical professionals and the law. This will be achieved by analysing sexuality and consent through the lens of disability theory and subsequently by including feminist theories on the notion of consent and of sexual activity generally where this serves to assist in coming to a genuine assessment of the nature and existence of consent to sexual activity for persons with mental disabilities. It is concluded that in order to ensure that genuine substantive consent to sexual activity on the part of the persons with mental illnesses is accurately assessed at both a civil and criminal level, a fusion of both feminist and disability theory into such assessments and adjudications is vital.

Law Reform Commission Consultation Paper: *Sexual Offences and Capacity to Consent*, Report of the Centre for Disability Law and Policy, National University of Ireland, Galway (2011) [Link](#)

Abstract: The issue of informed consent is closely connected to a broader debate on legal capacity and decision-making, currently underway in many countries following the entry into force of the UN Convention on the Rights of Persons with Disabilities (CRPD). As Ireland prepares to ratify the CRPD, the pressing need for general legislative reform in the area of legal capacity has been brought to the fore. This submission urges the Law Revision Commission to seek a solution to the tension between society’s duty to respect the rights and freedoms of people with disabilities, while also providing a legal response where people experience violence, exploitation or abuse. The underlying principle of this submission is

the need to balance the information, advice and support which individuals require to make informed decisions, with the freedom to make the same decisions as others, without discrimination on the basis of disability. At the level of policy and practice, any legal reform of sexual offences should also be accompanied by the implementation of various programmes to ensure that appropriate sexual education is provided, and that people with disabilities are supported in the decisions they choose to make (including the provision of advocacy support).

“Model of Intellectual Disability and the Relationship of Attitudes Towards the Sexuality of Persons with an Intellectual Disability,” *Sexuality and Disability*, Vol. 31 (2013) pp. 125—139 [Link](#)

Abstract: This article discusses the relationship between the model of intellectual disability held by someone (medical vs. social) and the attitudes they have toward sexuality of people with disabilities. This correlation was verified during the author’s own research conducted on students of several medical faculties such as nursing, public health, emergency medical services and physiotherapy. Significant correlations were found between the model held by an individual and their attitudes both in the cognitive and the affective-evaluative aspect. Higher scores for the medical model correlated with: (a) lower scores for most aspects of sexuality of people with intellectual disability, (b) perceiving them as asexual, © biological determinism in the sexual sphere. The social model concurred with positive values given to sexuality of people with intellectual disability and its normalization in the sphere of its determinants and symptoms.

“Factors Impacting on the Capacity to Consent in People with Learning Disabilities,” *Tizard Learning Disability Review*, Vol. 8, No. 3 (July 2003) pp. 11-20 [Link](#)

Abstract: Much of the discussion of capacity to consent has focused on how capacity can be assessed. However, in focusing on the assessment of capacity of people with learning disabilities, information from studies of human judgement and decision-making in the general population has been ignored. This paper reviews the main factors that affect an individual’s capacity to consent and examines the integration of research into these factors in the general population with that of people with learning disabilities. A person’s capacity to consent is considered to be affected by three main processes: comprehension (ability to understand and retain information), decision-making (ability to weigh up information and reach a decision) and communication (ability to communicate the decision made).The difficulties people with learning disabilities may have in these processes are discussed, and possible ways of overcoming these limitations are suggested.

“Striking a balance between safety and free expression of sexuality,” *Learning Disability Practice*, Vol. 18, No. 6 (2015) pp. 36-39 [Link](#)

Abstract: The British Mental Capacity Act of 2005 emphasises the importance of assessing people’s capacity to make decisions about their lives. This is especially important when assessing vulnerable people’s ability to consent to sexual relationships. This is a complex issue because a balance must be struck between the need to safeguard people with learning disabilities from exploitation and abuse, and the need to promote their autonomy. This article discusses these issues, and the role of learning disability nurses in balancing risk with choice when consent to a sexual relationship is explored. It concludes that there is a relationship between improved sexual education and empowering people to make decisions about sexual relationships.

Disability and LGBT Sexuality

“Experiences of adults with intellectual disabilities who identify as lesbian, gay, bisexual, or transgender within mainstream community: a systematic review of qualitative studies,” JBI Evidence Synthesis (January 2021) [Link](#)

Abstract:

Objective. The objective of this review is to identify, appraise, and synthesize the available qualitative evidence on the lived experiences of adults with intellectual disabilities who identify as lesbian, gay, bisexual, or transgender in mainstream society.

Introduction. People with intellectual disabilities who identify with a non-normative sexual orientation and gender identity (eg, lesbian, gay, bisexual, transgender, queer or questioning, intersex, asexual) are dually stigmatized due to the prevailing notion of ableism and heteronormativity within the wider society. This layered stigma can generate further segregation within society, increasing vulnerability in this population and limiting their facilitation of a meaningful and satisfying life. To date, there are no existing systematic reviews that have explored the proposed study.

Methods: The review considered qualitative studies that explored adults (aged 18 and over) who have a formal diagnosis of intellectual disability or mental retardation (preceding diagnosis) in conjunction with their lesbian, gay, bisexual, transgender, queer or questioning, intersex, or asexual identity. Following critical appraisal, 15 studies were included in this review. These studies were published between 1995 and 2018.

Results. None of the participants in this review identified as queer or questioning, intersex, or asexual. Therefore, the findings in this review solely report on the lived experiences of participants with intellectual disabilities who identify as lesbian, gay, bisexual, or transgender.

Conclusions. The synthesized findings indicated participants experienced a myriad of

intersecting issues and multilevel environmental challenges that had a profound and adverse impact on their daily lives and development of a positively evaluated sense of self. Recommendations for policy and practice are provided to initiate further awareness and give precedence to a minority group within society that tends to be under-represented and overlooked.

“Women Who Love: An Explorative Study on Experiences of Lesbian and Bisexual Women with a Mild Intellectual Disability in The Netherlands,” *Sexuality and Disability* (2018) pp. 249-264 [Link](#)

Abstract: Empirical research that addresses sexual orientation in people with an intellectual disability (ID) is limited, and very little is known regarding the personal experiences of lesbian and bisexual women with ID. This study set out to answer the question: What are the experiences of lesbian and bisexual women with a mild intellectual disability in the Netherlands? Ten lesbian and bisexual women (average age of 33 years) with a mild intellectual disability took part in our study comprising of semi-structured interviews. Participants reported that they had found it hard to talk to others about sensitive subjects such as their sexuality, and had been left to figure out information regarding their sexual orientation without support or guidance. Our results point to a lack of information, sexual education and role models when it comes to lesbian sex and women with an intellectual disability. Social contact was often limited, and participants experienced difficulties finding a partner. Furthermore, participants often had to cope with mental health problems and had struggled with loneliness, depression and addiction. Last but not least, our participants reported that they had been discriminated against. Coming out (revealing your sexual orientation) is not easy when you have an intellectual disability. To enable women with ID who have lesbian or bisexual feelings to understand and secure their sexual rights in their daily lives is important. Therefore, it is necessary to provide support in the following domains: sexual education and training, social contact and assertiveness.

“The experiences and support needs of people with intellectual disabilities who identify as LGBT: A review of the literature,” *Research in Developmental Disabilities* (Oct. 2016) [Link](#)

Abstract:

Background. People who identify as lesbian, gay, bisexual and transgender (LGBT) can face many challenges in society including accessing education, care and support appropriate to individual needs. However, there is a growing and evolving evidence base about the specific needs of people with intellectual disabilities (ID) in this regard.

Aims. The aim of this review was to explore the experiences of people with ID who identified as LGBT through an examination of studies that addressed their views and

highlighted specific issues, concerns and service responses.

Methods. A comprehensive search of relevant databases from February 1995 to February 2015 was conducted. The search yielded 161 papers in total. The search was narrowed and 37 papers were screened using rigorous inclusion and exclusion criteria. Finally, 14 papers were considered suitable for the review.

Results. The data were analysed and key themes identified that included accessing health services, gender and sexual identity, attitudes of people with ID regarding their LGBT status, and education, supports and therapeutic interventions.

Conclusions. There is a need for service providers and carers to be more responsive to the concerns of people with ID who identify as LGBT to improve their health and well-being by reducing stigma and discrimination and by increasing awareness of their care and support needs. The implications are discussed in terms of policy, education, research and practice developments.

“Homosexuality among people with a mild intellectual disability: an explorative study on the lived experiences of homosexual people in the Netherlands with a mild intellectual disability,” *Journal of Intellectual Disability Research* (March 2013) [Link](#)

Abstract:

Background. Empirical research on homosexuality among people with an intellectual disability (ID) is limited and, to date, very little is known regarding the personal experiences of gay and lesbian people with an ID. This study set out to answer the question: What are the lived experiences of a specific cohort of homosexual people with an intellectual disability living in the Netherlands?

Method. To answer this question, a qualitative study was performed in which 21 people with a mild ID were interviewed via semi-structured interviews. In this study, 19 participants were men and two were women (average age = 40.5 years).

Results. Participants reported positive and negative experiences, and talked about their gay or lesbian identity. Almost half of the participants (n = 10) reported that they had experienced sexual abuse including partner violence (n = 6). Additionally, they indicated that there was a lack of support for homosexual people with an ID.

Conclusion. Specific problems impact the lives of homosexual people with ID, namely the high prevalence of negative sexual experiences, the lack of support, training and sex education, and their search for a suitable partner.

“Who’s Missing? Awareness of Lesbian, Gay, Bisexual and Transgender People with Intellectual Disability,” *Sexuality and Disability*, Vol. 29 (2011) pp. 175–180 [Link](#)

Abstract: This article arose from an Australian project designed to develop educational and training material in relation to lesbian, gay, bi-sexual and transgender (LGBT) people with disability. The project was supported by the Queensland Association of Healthy Communities (QAHC) and the Queensland Centre for Intellectual and Developmental Disability (QCIDD). A resource was developed and its aim is to create greater awareness and understanding within the community that LGBT people with intellectual disability exist and to provide education and training to disability organizations. We aim to present the complexity of issues which prevent LGBT people with intellectual disability from living full lives and having opportunities for sexual expression.

Sexuality Over the Lifespan

“Sexuality and developmental disability: Obstacles to healthy sexuality throughout the lifespan,” *Developmental Disabilities Bulletin*, No. 1 & 2 (2006) pp. 137 155. [Link](#)

Abstract: This paper presents a lifespan perspective of sexuality issues for individuals with developmental disabilities. Individuals with developmental disabilities are human beings who have historically been denied the right to express their sexuality or engage in sexual relationships due to misconceptions or negative attitudes. Using a hypothetical case to illustrate the challenges experienced by individuals with disabilities, human rights violations and the need for education and appropriate sexual information are highlighted. Issues such as eugenics, vulnerability to abuse, self esteem, and individual differences are also discussed. Recommendations for practice are provided.

Understanding the Law

“Sexual relationships in adults with intellectual disabilities: understanding the law,” *Journal of Intellectual Disability Research*, Vol. 51, No. 3, (March 2007) pp. 197-206 [Link](#)

Abstract: Adults with intellectual disabilities (IDs) are known to be very vulnerable to sexual abuse. This may result partly from their lack of sexual knowledge and their powerless position in society. It could also be exacerbated by an ignorance of the law. This study investigates their understanding of the law relating to sexuality.

Method. Understanding of the law on sex, consent and abuse was assessed in 60 adults with IDs (mean age 37.6 years) and 60 young people aged 16-18 years (deemed in law capable of consenting to a sexual relationship). Questions were wide ranging, including general laws around sexuality and abuse, as well as the law relating to sexual relationships and ID.

Results. There were significant differences between the two groups: adults with IDs had a very limited understanding of the general laws relating to sexuality (e.g. age of consent, incest, abuse), as well as the law relating to sexuality and IDs (e.g. whether they could have sexual relationships, whether they were allowed to marry, what protection they should expect from the law). Young people without disabilities showed a better understanding, both for general laws and for those relating specifically to adults with IDs.

Conclusions. These findings show that there is a need to educate people with IDs about the laws relating to sexuality. It is important for people to understand the law and, given the high rates of sexual abuse perpetrated against people with ID, it is essential for them to benefit from the protection the law affords.

Sex Education

“Sex: What Is the Big Deal? Exploring Individuals' with Intellectual Disabilities Experiences with Sex Education,” Qualitative Health Research (February 2022) [Link](#)

Abstract: This article offers perspectives shared by self-advocates in the first phase of a community-based participatory research project undertaken to address barriers that individuals with intellectual disabilities face with respect to sexual health knowledge. Using descriptive qualitative methods, we interviewed 19 individuals with intellectual disability about their experiences and knowledge related to sexual health. The research question guiding this project was: What are self-advocates' with intellectual disabilities experiences learning about sexual health and sexuality? The findings highlight that participants faced barriers and lack of access to sexual health education, and while they learned about sexual health through formal sexual health education, frequently this knowledge came through lived experience. Finally, the findings underscore that participants knew what they wanted with respect to sexual health education and offered recommendations. The importance of accessible sexual health education for self-advocates that supports their rights and desires to express their sexuality and sexual agency is highlighted.

“Access, Autonomy, and Dignity: Comprehensive Sexuality Education for People with Disabilities,” National Partnership for Women and Families (September 2021) [Link](#)

Abstract: This issue brief focuses on the right of access to sex education and barriers for people with disabilities, and includes policy recommendations to ensure that sex ed is truly accessible for all people.

“Sexual Health Education: A Missing Piece in Transition Services for Youth with Intellectual and Developmental Disabilities?” The Journal of Rehabilitation, Vol. 84, No. 3 (July-Sept. 2018) [Link](#)

Abstract: Transitioning to adult life is a complex time for all young people and includes assuming adult roles in work, independent living, and social relationships. As young adults with intellectual and developmental disabilities (IDD) access a broader array of social settings in their transition, including higher education, work, and independent living situations, social issues take on greater importance. Maintaining age appropriate relationships, including sexual relationships, is a critical piece of inclusion. However, students with IDD are not afforded the same access to sexual health information offered to other students. This lack of information and opportunity for development leaves young adults with IDD unfamiliar with many aspects of human sexuality and social relationships and potentially unprepared to function in adult social settings. This article provides an overview of the scope and importance of sexual health knowledge for young adults with IDD, limitations in current educational practices, practices and resources for addressing sexual health knowledge for this population, and suggestions for ways that rehabilitation counselors can ensure attention to this area within the transition process without going beyond our scope of practice.

**“Sexuality Education for People with Disabilities, “SIECUS Report (Feb/Mar 2001)
[Link](#)**

Abstract:

This special report published by SIECUS (Sex Information and Education Center of the United States) addressed a wide range of issues relevant to people with disabilities in general and people with developmental disabilities in particular.

This SIECUS Report begins with an article titled “Becoming Sexually Able: Education to Help Youth with Disabilities.” It includes a lesson plan that was developed by Mitch Tepper, founder of The Sexual Health Network and SexualHealth.com as well as a member of the SIECUS Board of Directors.

Next, Michelle Ballan, who has just completed her doctoral work at the University of Texas and will soon become a professor at the Columbia University School of Social Work, talks about the role that parents must play in educating their children with disabilities. Her article titled “Parents As Sexuality Educators for Their Children with Developmental Disabilities” says that young people learn more when sexuality information is repeated and reinforced both at home and school.

Melvyn Littner, Lorna Littner, and Mary Ann Shah write in their article “Sexuality Issues for the Disabled: Development of a Unified School Policy” about their project to attempt to address this issue. The article includes the guidelines eventually developed by administrative, staff, and parent representatives of P.721—Queens Occupational Training Center in New York City. Their work is very impressive.

Position of the National Down Syndrome Society - [Link](#)

Policy: Human sexuality encompasses an individual's self-esteem, interpersonal relationships and social experiences relating to dating, marriage and the physical aspects of sex. Sex education, appropriate for the developmental level and intellectual attainment of individuals with Down syndrome, adds to life quality by developing healthy sexuality, reducing the risk of sexual abuse, avoiding sexual misunderstandings, preventing disease transmission, preventing unwanted pregnancy and alleviating other problems related to sexual function.

“Relationships + Sexuality,” Down Syndrome Resource Foundation - [Link](#)

Abstract: It is commonly thought that sexuality is not a concern for people with Down syndrome. People with Down syndrome and other developmental disabilities are often assumed to be uninterested in sex and sexuality, to not be having sex or physical intimacy, and that their interests should match their cognitive age or abilities, not their biological age. They may be seen as asexual, eternally young, or too innocent to be concerned with sexuality or to need sexual health education. However, that is a myth. Sexuality is very important and interesting to people with Down syndrome. Comprehensive sexual health education, which encompasses these topics plus the thoughts and feelings that accompany them, is important for everybody.

“A mixed methods evaluation of Girls' Talk+: A sexuality education programme for girls with mild intellectual disabilities,” Journal of Applied Research in Intellectual Disabilities (July 2022) [Link](#)

Abstract:

Background. Girls with a mild intellectual disability generally receive less sexuality education than their non-disabled peers, while their needs for sexual knowledge are possibly greater. This study aimed to evaluate the effect and process of a new sexuality education programme (Girls' Talk+), focused on sexual health among girls with a mild intellectual disability in the Netherlands.

Methods. A mixed methods approach was applied, using participant questionnaires (n = 249), logs written by trainers (n = 17) and interviews with trainers (n = 10). Descriptive statistics and linear regression models were used to analyse the quantitative data. Several coding phases were used to analyse the interviews.

Results. This study provides some indication that Girls' Talk+ has positive results on improving knowledge, attitude, and self-efficacy in relation to sexual health as well as trainer and participant satisfaction with the programme.

“Experiences of teachers, educators, and school counselors about the sexual and reproductive health of educable intellectually disabled adolescent girls: a qualitative study,” *Reproductive Health* (April 2022) [Link](#)

Abstract:

Background. Adolescents with intellectual disabilities are probably twice as many people without intellectual disabilities to be sexually abused by family members, caregivers, close relatives, and others in the community. Sex education and training are essential components of children's and teenagers' education and human rights, as well as a source of worry for parents and society. While the parents are thought to be the most accessible choice as sexual educators, they often do not fulfill this role. Therefore, professional teachers and trainers who have undergone sex education courses for mentally retarded adolescents are more reliable sources to provide the sexual information in terms of their educational role. This study aimed to determine the experiences of teachers, educators, and school counselor parents regarding the sexual and reproductive health of educable intellectually disabled adolescent girls.

Methods. This was a qualitative content analysis study. 35 participants were selected via purposive sampling with maximum variation, and data were collected through in-depth individual interviews, focus group discussions and field notes, and analyzed using the conventional qualitative content analysis method simultaneously.

Results. Three subcategories have emerged: "knowledge and professional experience of teachers, educators, and school counselors with how to educate and care for adolescent sexual health", "proficiency of teachers, educators, and school counselors in guiding families in solving their child's sexual problems", "attitude of teachers, educators, and school counselors towards sexual behaviors and sexual education of adolescents" which formed the main category of "teachers, educators, and school counselors' inefficiency in maintaining ID adolescent girls' sexual and reproductive health".

Conclusions. Teachers, educators, and school counselors encounter a variety of issues related to the sexual and reproductive health of intellectually impaired teenage females, as a consequence of the findings. As a result, efforts should be made to enhance knowledge and skill development, as well as the evolution of negative attitudes. Therefore, the teaching of sexual guidelines for teenagers with mental impairments should be included in the agenda of the country's educational policies. Teachers and educators should be taught by health experts via the holding of in-service training courses.

“Persons with Intellectual Disability: Sexual Behaviour, Knowledge and Assertiveness,” *Zdr Vdrst Slovenian Journal of Public Health* (March 2021) [Link](#)

Abstract:

Background. Persons with ID most often have incomplete, contradictory and imprecise knowledge of sexuality and sexual intercourse itself. They are not provided with sufficient information on their own body and sexuality, and are often discouraged from and sanctioned for trying to sexually express themselves. Sexual abuse due to low sexual assertiveness is also common.

Aim. The principal aim of this study was to establish the presence or absence of sexual activity in adults with ID residing in institutional housing, as well as the level and structure of their knowledge of sexuality, their sexual assertiveness and preparedness to react in a sexually dangerous situation.

Methods. The sample consisted of 100 participants with ID residing in institutional housing. The instruments used included the General Sexual Knowledge Questionnaire, What-if test and Hulbert index of sexual assertiveness. Comparative statistics included coefficient of linear correlation and multiple regression analysis.

Results. The results showed that 82% of the participants are sexually active. Most participants admitted to sometimes having sexual intercourse against their wishes as well as to having difficulty asserting themselves. Their knowledge of pregnancy, contraception and sexually transmitted diseases was very low. Female participants and those that reported having sexual intercourse had more sexual knowledge and were also more sexually assertive.

Conclusion. Knowledge of sexuality and sexual assertiveness of persons with ID residing in institutional housing is very low. Additional information on sexuality is necessary, as well as support in learning to express their own desires and to deal with unwanted sexual activity.

“Evidences of an Implemented Training Program in Consensual and Responsible Sexual Relations for People with Intellectual Disabilities, International Journal of Environmental Research and Public Health (February 2021) [Link](#)

Abstract: *Background.* While there is a growing awareness of the rights of individuals with intellectual disabilities, very limited progress has been made in supporting these people to create and maintain intimate and personal relationships. *Methods.* This paper reports the results from a program aimed at promoting responsible and consensual sexual relations of adults with intellectual disabilities. Of the 44 participants, 31.8% were women and 68.2% were men aged 22 to 67 years. Pre and post measurements regarding the attitudes toward sexual relations were taken, and difficulty and discrimination indexes were calculated. *Results.* Statistically significant improvements were identified in the overall measurements, as were they for the domains of privacy, safety, and respect. The difficulty index changed from 0.67 to 0.79 in a pre-post assessment, denoting more positive attitudes. This and other

results support the relevance and usefulness of the intervention program and encourage further intervention efforts.

“Sexual health education for adolescents and young adults with intellectual and developmental disabilities: recommendations for accessible sexual and reproductive health information,” *The Lancet Child and Adolescent Health* (September 2020) [Link](#)

Abstract: Sexual and reproductive health is an important aspect of human development, but discussions with adolescents and young adults on this topic are often challenging for health-care providers. As a result, many adolescents and young adults do not receive appropriate, comprehensive sexual education, despite recognition from WHO and the UN that access to this education is a human right. Adolescents and young adults with mild to moderate intellectual or developmental disability, or both, are just as likely to be sexually active as are their peers without disability; however, these individuals are less likely to receive comprehensive sexual education. To ensure adequate comprehensive sexual education for adolescents and young adults with intellectual and developmental disabilities, sexual health educators should facilitate conversations about sexual and reproductive health that are non-judgmental and sexually inclusive. Such initiatives should use an educational framework grounded in universal design for learning, including use of multiple media types with clear, concise language and images.

“Sexuality and personal relationships for people with an intellectual disability. Part I: service-user perspectives,” *Journal of Intellectual Disability Research* (November 2009) [Link](#)

Abstract:

Background. Despite a recent ideological shift towards the recognition of sexual autonomy for people with an intellectual disability (ID), there are continuing social and cultural barriers to sexual expression. Part I of the current two-part study assessed the sexual knowledge, experiences and aspirations of service users through focus groups and also examined their perceptions of impediments to achieving sexual autonomy.

Method. Thirty-two participants (20 male, 12 female) attending an ID service participated in focus groups delineated by gender and age group (13-17 years; 18-30 years; 31+ years).

Results. Analysis of the focus groups showed that service users, especially those over the age of 18 years, had an understanding of their sexual rights but also identified a number of social and cultural barriers that they felt prevent them from achieving sexual autonomy. Those under the age of 18 years had only rudimentary knowledge of sexuality issues, for example pregnancy and sexual anatomy, but aspired to relationships and marriage similar to those over the age of 18 years. Family and staff attitudes appeared to be very influential in the

views of respondents. All service users had received some form of sex education, although the benefits of such education appeared most enduring for those over 18 years.

Conclusion. Service users had an understanding of their sexual rights and the social and environmental barriers that prevent them from fulfilling their rights. The provision of sex education training and promotion of positive attitudes towards appropriate sexual expression is critical to the realization of sexual autonomy for people with an ID.

“Women with intellectual disabilities talk about their perceptions of sex, *Journal of Intellectual Disability Research* (March 2013) [Link](#)

Abstract:

Background. Sexuality is learned through sexual socialisation that women with intellectual disabilities (IDs) understand and express. Rules of sexual engagement for these women can include barriers for their socialisation, intimate partner selection, and sexual expression. These rules can become more limiting when coupled with rules of femininity that encourage sexual restraint for women.

Methods. This ethnography explored how women with IDs perceived their sexuality and how sexuality functioned in their lives. Sources of data included 48 multiple and in-depth interviews and observations with 14 women. This article specifically describes how the women constructed 'sex' and how they described experiencing sex as two of their multiple expressions of sexuality in this study.

Results. Most of the women had very limited and exclusively heterosexual sexual experiences, and the majority of women reported practicing abstinence. Criteria they identified for sex included having protected sex, marital and monogamous sex for the purpose of procreation or parenting, and having feelings for a sexual partner. Most held negative perceptions of sex they attributed to fear of the first act, fear of experiencing negative consequences, physiological concerns about the act, and perceived or actual lack of pleasure.

Conclusions. Although the women displayed some sense of self-determinism in their sexual behaviour, negative perceptions of sex resulted in self-imposed abstinence predicated by fear of intercourse, intimacy, or outcome. Central to their sexuality education then is increasing self-efficacy perceptions and performance of safer sex practices to prevent negative sexual consequence. Sexuality education from a positive perspective that enhances their sexual self-determinism and encourages sexual health is recommended.

“Capacity to consent to sexual relationships in adults with learning disabilities,” *Journal of Family Planning and Reproductive Health Care*, Vol. 29, No. 3 (2003) [Link](#)

Abstract: People with learning disabilities used to be seen as asexual or promiscuous and were discouraged from expressing their sexuality. However, with the growth of the rights movement, attention has turned to the dilemma of how to both empower and protect people with learning disabilities in relation to their sexuality. A recent research project showed that, on average, adults with learning disabilities knew much less about sex and understood much less about sexual abuse than non-disabled young people aged 16 years. Adults with learning disabilities of ten lacked important information and knowledge in a number of key areas, including pregnancy, contraception, sexually transmitted diseases, legal aspects of sex and sexual health (for example, 60% had not heard of AIDS and only 18 % could identify condoms as a way of reducing the chance of HIV infection). Non-disabled young people had a far greater knowledge of all these areas. Adults with learning disabilities also showed limited understanding of consenting and non-consenting situations and often considered a consenting situation as wrong, while non-consenting situations were sometimes not recognized as abusive. Some (55 %) of the adults with learning disabilities said they had sex education, as compared with 98% of young people. Thus, people with learning disabilities who had had sex education, did significantly better on sexual knowledge and vulnerability assessments.

“Discrimination, Sexuality and People with Significant Disabilities: Issues of Access and The Right to Sexual Expression in the United States,” Disability Studies Quarterly, Vol. 22, No. 4 (Fall 2002) pp. 9-27 [Link](#)

Abstract: A review of legislation, policy and practice was conducted to outline the conflicting issues that contribute to the currently widespread discrimination of people with significant disabilities in the United States and their access to sexuality education and expression. Although many individuals with significant disabilities face discrimination on multiple levels, barriers to sexuality seem pervasive in most environments that people encounter. While some individuals with significant disabilities have been successful in establishing and maintaining intimate relationships, many continue to face isolation in the communities in which they live. This paper will outline the issues that surround and contribute to the discrimination of people with significant disabilities in the United States with regard to their right to sexuality and discuss the need for new policies that will serve as potential remedies for this national problem.

“The Continuum of Support for Building Intimacy Knowledge in College for Students with Intellectual and Developmental Disability, Doctoral Dissertation, University of South Carolina (2019) [Link](#)

Abstract: Adults with intellectual disability report the same relational and sexual intimacy needs as those without disability, yet experience barriers in accessing intimacy education and engaging in intimacy. Post secondary education (PSE) programs for students with intellectual

disability allow for college students to experience a higher level of autonomy in choice-making they may not have experienced in their family home. The Continuum of Support for Intimacy Knowledge in College Survey (CoSIK-C) was used to examine how PSE programs support college students in building their intimacy knowledge, intimacy education professional development opportunities for PSE staff members, and staff perceptions on factors that could influence whether students engage in intimacy or access intimacy education. Frequency of support, context in which support is provided, and types of resources and services used to build intimacy knowledge were identified and varied across programs. Half of the respondents indicated that their PSE program provides support in building students' intimacy knowledge two times per year or less, with 15% of programs not providing any support related to building intimacy knowledge. Contextually, support is most frequently provided proactively for all students, and one-fourth of PSE programs provide support reactively based on a student's negative experience with intimacy. Intimacy topics most frequently discussed include personal hygiene and social skills and cues related to dating, while topics such as unplanned pregnancy, biological and reproductive functioning, sexual and gender identity, and masturbation were not discussed in 40-50% of PSE programs. Half of PSE programs do not offer intimacy education professional development to staff members, yet almost two-thirds of respondents indicated that students in their program consider learning about intimacy a priority. Staff perspectives on influential factors that could affect whether a student enrolled in the PSE program can access intimacy education or engage in intimacy are identified. Implications for practice and future research are provided.

Sexuality issues and the voices of adults with intellectual disabilities: A systematic review of the literature, *Research in Developmental Disabilities* (Mach 2018) pp. 124-138 [Link](#)

Abstract:

Background. There is a growing and evolving research base regarding sexuality issues and adults with intellectual disabilities. Individuals can face challenges, including the right to express their sexuality and to access necessary education and supports.

Aims. This systematic review explores sexuality experiences, the views and opinions of adults with intellectual disabilities and highlights areas for future practice developments.

Methods. A comprehensive search of relevant databases from January 2006 to December 2016 was carried out. Following the application of explicit inclusion and exclusion criteria, 23 papers were deemed suitable for the review.

Results. The data were analysed and key themes were identified that included: autonomy v's risk of harm, knowledge and sexuality, relationships and intimacy, self-determination and

taking control, and encouragement and supports.

Conclusions. Adults with intellectual disabilities need education and support to express their sexuality and to meet individual needs.

Feature Issue on Sexuality and People with Intellectual, Developmental and Other Disabilities, Impact, Volume 23, No. 2 (Spring/Summer 2010) [Link](#)

Abstract: This issue of the Impact newsletter contains short article about sexuality written by and for people with developmental disabilities, families, and service providers. Titles include: Identity, Disability, and Sexuality: Reflections From a Son and His Father; Self-Advocates Speak Up About Sex; Sexuality Meets Intellectual Disability: What Every Parent Should Know; Destination – Adulthood: Preparing Your Child for Puberty and Adolescence; Becoming a Woman: Teaching Healthy Sexuality to My Daughter; Sexual Expression for Adults with Disabilities: The Role of Guardianship; ex, Disability and the DSP: Ethically Supporting Sexual Choices; Coming Out: A Daughter-Mother Conversation; People with Disabilities and the Federal Marriage Penalties.

Cerebral Palsy and Sexuality

“Sexuality of Young Adults with Cerebral Palsy: Experienced Limitations and Needs,” Sexuality and Disability (2011) pp. 119-128 [Link](#)

Abstract: The objective of this study is to describe the problems young adults with Cerebral Palsy (CP) experience in the various stages of the sexual response cycle, and the physical and emotional obstacles they experience with sexuality. In this prospective cohort study 74 young adults (46 men; 28 women) with CP and average intelligence participated, aged 20–24 years. Twenty percent of these young adults with CP experienced anorgasmia, 80% reported physical problems with sex related to CP and 45% emotional inhibition to initiate sexual contact. In 90% of the participants, sexuality had not been discussed during the rehabilitation treatment. Many adolescents reported wanting information about the impact of CP on sexuality and reproduction (35%), about interventions (26%), tools and medicines (16%) and about problems with their partner (14%). Young adults with CP can experience various problems or challenges with sexuality. For preventing sexual difficulties and treating sexual problems, health care professionals need to proactively take the initiative to inform young people with CP about sexuality.

Conceptualizing Sex with Cerebral Palsy: A Phenomenological Exploration of Private Constructions of Sexuality Using Sexual Script Theory, International Journal of Social Science Studies, Vol. 2, No. 2 (April 2014) [Link](#)

Abstract:

This study explored how people with cerebral palsy (CP) negotiated and perceived their sexual interactions with others. In doing so, this research discusses participant conceptualizations of sexuality with CP. In-depth, semi-structured interviews were conducted with two women and five men with moderate to severe cerebral palsy from Canada and Australia. The interview discourse focused on how, if at all, private/internal constructions of sexuality influenced the way in which participants expressed and negotiated their sexuality. Interview data were thematically analyzed using NVivo and manual line-by-line analysis.

Notably, accepting oneself was important to people with cerebral palsy's sense of sexuality. By critically discounting exclusionary or negative sexual schema, people with cerebral palsy learn to be more accepting of their abilities and attribute positive conceptualizations to themselves and their sexual identity. Participants had mixed perceptions of body esteem as an aspect of their sexuality. Downward social comparisons were associated with positive body esteem. Negative body esteem could be an after effect of the lack of resources to support people with cerebral palsy in their sexual participation (i.e., sexual surrogates, workers, sexual facilitation from care providers, privacy or accessibility to transport) (see Earle, 1999). Participants also believed their sexual agency was constrained. For instance, they were apprehensive about explicitly asking for what they required from a sexual partner for fear that they may seem overly demanding, which could frustrate a sexual partner or end a relationship.

For people with CP personal agency yields more satisfying socio-sexual outcomes. The present study suggests that people with cerebral palsy do in fact recognize that being sexually agential would increase their sense of sexual satisfaction and empowerment. Further, participants believed that sexual agency could be enhanced with personal effort. In this regard, the ability to make (and exercise) choice when negotiating sexuality reinforces conceptualizations of oneself as a sexually desirable being

“The Search for Sexual Intimacy for Men with Cerebral Palsy,” *Sexuality and Disability* (December 2000) [Link](#)

Abstract: This study explores the accounts of the search for sexual intimacy for 14 men with cerebral palsy revealed a range of issues and impediments and a complex intersubjective process in their search for a lover. Yet, despite an adverse sociocultural context of disability and desirability, most of the men had experienced long-term sexual relationships. The cultivation of several aspects of self and society was noted as facilitating the possibility of their establishing sexual intimacy with others.

Sexual Activity of Young Adults with Cerebral Palsy, *Doctoral Dissertation*, Nova Southeastern University (2022) [Link](#)

Abstract: Sexual activity is an occupation within the scope of occupational therapy. Few studies address sexual activity of young adults with cerebral palsy (CP) from an occupational perspective. This study examines prevalence of sexual activity, interest, and satisfaction level for young adults with CP. It traces possible effects of sexual orientation, gender identity, and relationship status on sexual activity, using a quantitative non-experimental cross-sectional research design. The study is based on 82 young adults with CP aged 18–39 with access to web-based communication. The researcher collected demographic information and data from the Patient-Reported Outcomes Measurement Information System (PROMIS) Sexual Function and Satisfaction (SexFS) Version 2.0 via REDCap. Data analysis includes descriptive statistics and a one-way ANOVA to compare the effects of sexual orientation, gender identity, and relationship status on levels of sexual interest and satisfaction. The results indicate young adults with CP identify more as LGBTQAI+ than the general population and engage in a range of sexual activities. Their mean scores for interest and satisfaction fall within the average range. Cisgender men have more interest in sexual activity than cisgender women, while cisgender women report greater levels of satisfaction. The researcher found no difference between straight and bisexual individuals. Individuals in a relationship expressed more interest and satisfaction than single individuals. Knowledge of diverse sexual activities, gender identities, sexual orientations, and relationships statuses of young adults with CP, and their interest and satisfaction levels, can help occupational therapists and other professionals become more attuned to the needs of these groups

Autism and Sexuality

“Sex and Sexuality in Autism Spectrum Disorders: A Scoping Review on a Neglected but Fundamental Issue,” Brain Sciences (October 2022) [Link](#)

Abstract: ASD consists of a set of permanent neurodevelopmental conditions, which are studied with social and communication differences, limited interests, and repetitive behaviors. Individuals with ASD have difficulty reading eye gestures and expressions, and may also have stereotyped or repetitive language, excessive adherence to routines, fixed interests, and rigid thinking. However, sexuality in adolescents and young adults with ASD is still a poorly studied and neglected issue. This review aims to evaluate sexual function and behavior in individuals with ASD to foster a greater understanding of this important, although often overlooked, issue. This review was conducted by searching peer-reviewed articles published between 01 June 2000 and 31 May 2022 using the following databases: PubMed, Embase, Cochrane Database, and Web of Science. A comprehensive search was conducted using the terms: "Autism" OR "ASD" AND "Sexuality" OR "Romantic relation" OR "sexual behavior" AND/OR "sexual awareness". After an accurate revision of 214 full manuscripts, 11 articles satisfied the inclusion/exclusion criteria. This review found that, although individuals with ASD may have sexual functioning, their sexuality is characterized by higher prevalence rates of gender dysphoria and inappropriate sexual behavior. Furthermore, sexual awareness is reduced in this patient population, and the prevalence of

other variants of sexual orientation (i.e., homosexuality, asexuality, bisexuality, etc.) is higher in adolescents with ASD than in non-autistic peers. Sexual health and education should be included in the care path of patients with ASD in order to improve their quality of life and avoid/reduce inappropriate and risky behaviors.

“Sexual Orientation in Autism Spectrum Disorder,” Autism Research (January 2018)

[Link](#)

Abstract: Clinical impressions suggest a different sexual profile between individuals with and without Autism Spectrum Disorder (ASD). Little is presently known about the demographics of sexual orientation in ASD. Sexual Orientation was surveyed using the Sell Scale of Sexual Orientation in an international online sample of individuals with ASD (N = 309, M = 90, F = 219), aged (M = 32.30 years, SD = 11.93) and this was compared to sexual orientation of typically-developing individuals (N = 310, M = 84, F = 226), aged (M = 29.82 years, SD = 11.85). Findings suggested that sexual orientation was contingent on diagnosis (N = 570, $\chi^2(9) = 104.05$, $P < 0.001$, $\phi = 0.43$). In the group with ASD, 69.7% of the sample reported being non-heterosexual, while in the TD group, 30.3% reported being non-heterosexual. The group with ASD reported higher rates of homosexuality, bisexuality and asexuality, but lower rates of heterosexuality. The results support the impression that non-heterosexuality is more prevalent in the autistic population. Increased non-heterosexuality in ASD has important clinical implications to target unique concerns of this population, and suggests a need for specialized sex education programs for autistic populations for increased support and awareness. *Autism Res* 2018, 11: 133-141. © 2017 International Society for Autism Research, Wiley Periodicals, Inc.

Lay Summary: Research suggests that individuals with Autism Spectrum Disorder (ASD) report increased homosexuality, bisexuality, and asexuality, but decreased heterosexuality. It is important to increase awareness about increased non-heterosexuality in ASD among autistic populations, medical professionals and care-takers, so as to provide specialized care, if needed and increase support and inclusion for non-heterosexual autistic individuals.

“Gender identity and sexual orientation in autism spectrum disorder,” Autism (November 2018) [Link](#)

Abstract: Clinical impressions indicate that there is an over representation of gender-dysphoria within the autism spectrum disorder. However, little is presently known about the demographics of gender-identity issues in autism spectrum disorder. Based upon what little is known, we hypothesized that there would be an increased prevalence of gender-dysphoria among those with autism spectrum disorder compared to a typically developing population. We surveyed gender-dysphoria with the Gender-Identity/Gender-Dysphoria Questionnaire among 90 males and 219 females with autism spectrum disorder and compared these rates to those of 103 males and 158 females

without autism spectrum disorder. When compared to typically developing individuals, autistic individuals reported a higher number of gender-dysphoric traits. Rates of gender-dysphoria in the group with autism spectrum disorder were significantly higher than reported in the wider population. Mediation analysis found that the relationship between autistic traits and sexual orientation was mediated by gender-dysphoric traits. Results suggest that autism spectrum disorder presents a unique experience to the formation and consolidation of gender identity, and for some autistic individuals, their sexual orientation relates to their gender experience. It is important that clinicians working with autism spectrum disorder are aware of the gender-diversity in this population so that the necessary support for healthy socio-sexual functioning and mental well-being is provided.

“Sexuality and Gender Issues in Individuals with Autism Spectrum Disorder,” Child and Adolescent Clinics of North America (July 2020) [Link](#)

Abstract: This article reviews relevant literature on sexuality in individuals with autism spectrum disorder (ASD). Findings reveal a growing awareness of desire for sexual and intimate relationships in individuals with ASD. However, core impairments of ASD lead to difficulties establishing requisite knowledge and skills necessary to attain a healthy sexuality and facilitate relationships. Consequently, individuals with ASD present with increased risk of engaging in inappropriate sexual behaviors and sexual victimization than their typically developing peers. The literature asserts the need to implement effective sexual education programs to assist in development of healthy sexual identity and relationships that meet each individual's needs.

“Autism-spectrum disorders in adolescence and adulthood: focus on sexuality,” Current Opinion in Psychiatry (November 2017) [Link](#)

Abstract:

Purpose. The combination of the core symptoms, characterizing individuals with autism-spectrum disorder (ASD), can lead to problems in romantic relationships and sexual functioning. The purpose of this article is to review studies on sexuality in individuals with ASD published since January 2016.

Findings. Individuals with ASD and especially women show a higher diversity in sexual orientation in comparison with the non-ASD population. Furthermore, ASD women are more frequently in a relationship and usually report more previous sexual experiences. Up to now, sexual education programs specifically addressing the needs of the ASD population were scarce, which was criticized by patients, their parents, and caregivers. With the development of the Tackling Teenage Training program, a psychoeducational intervention designed specifically for ASD individuals was introduced, leading to significant improvements in psychosexual functioning and knowledge. Such programs are needed because a considerable

rate of problematic sexual behaviors, including public masturbation and paraphilic sexual interests were found in the ASD population.

Summary. Just like their typically developing counterparts, individuals with ASD show the whole range of normal-to-problematic sexual behaviors. Improving sexual knowledge could lead to less inappropriate sexual behaviors and could improve sexual health as part of a healthy and satisfying life.

Health Care Providers

“Access to Sexual Health Services and Support for People with Intellectual and Developmental Disabilities: an Australian Cross-sector Survey,” *Sexuality Research and Social Policy* (June 2022) [Link](#)

Abstract:

Introduction. People with intellectual and developmental disabilities under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) have the right to access sexual health services including information, education, and support. Little is known about the capacity of sexual health professionals to provide these services.

Methods. Using an observational research design, this study utilised a descriptive survey tool (PASH–Ext) that also encompassed a standardised measure, with a cross-sectional purposive sample of 52 Australian sexual health professionals. Data was collected in 2020.

Results. Just over half of the participants reported having received training in their preservice education to work with people with intellectual and developmental disabilities, of these 60% held the view that people with intellectual and developmental disabilities would not feel embarrassed receiving sexual health information and support.

Conclusion. The study found that training is both important to the professionals’ preparedness to work with people with intellectual and developmental disabilities, and that these professionals advocate for the continuation of this training in pre-service courses and additional training in post service education for sexual health workers.

“Our Sexuality, Our Health: A Disabled Advocate’s Guide to Relationships, Romance, Sexuality and Sexual Health,” *Office of Developmental Primary Care, University of California at San Francisco* (2018) [Link](#)

Abstract: This guide has section discussing: sexuality education; talking to your doctor about sex and family planning; dating; sex; marriage; pregnancy and parenting.

“Healthcare providers’ role in providing sexual and reproductive health information to people with intellectual and developmental disabilities: A qualitative study,” *Journal of Applied Research in Intellectual Disabilities* (July 2022) [Link](#)

Abstract:

Background. Individuals with intellectual and developmental disabilities demonstrate disparities in sexual and reproductive health (SRH) compared to individuals without disabilities (e.g., lack of sexual education and knowledge, increased rates of abuse, unplanned pregnancies and sexually transmitted infections). Therefore, the purpose of this study was to identify topics healthcare providers address and perceived barriers and supports to SRH education.

Methods. We conducted semi-structured interviews with healthcare providers (N = 12).

Results. Providers address relationships, safety, protection and appropriate sexual behaviours with clients with intellectual and developmental disabilities. Parent education and client-centred care were identified as supports, while the patient's level of understanding, the provider's lack of knowledge or access to resources and to appropriate referrals were identified as barriers to SRH education.

Conclusion. Future studies are needed to link providers to resources they can use to provide comprehensive, accessible SRH education for clients with intellectual and developmental disabilities.

“Promoting Healthy Sexuality for Children and Adolescents With Disabilities,” *Pediatrics* (July 2021) [Link](#)

Abstract: This clinical report updates a 2006 report from the American Academy of Pediatrics titled "Sexuality of Children and Adolescents With Developmental Disabilities." The development of a healthy sexuality best occurs through appropriate education, absence of coercion and violence, and developmental acquisition of skills to navigate feelings, desires, relationships, and social pressures. Pediatric health care providers are important resources for anticipatory guidance and education for all children and youth as they understand their changing bodies, feelings, and behaviors. Yet, youth with disabilities and their families report inadequate education and guidance from pediatricians regarding sexual health development. In the decade since the original clinical report was published, there have been many advancements in the understanding and care of children and youth with disabilities, in part because of an increased prevalence and breadth of autism spectrum disorder as well as an increased longevity of individuals with medically complex and severely disabling conditions. During this same time frame, sexual education in US public schools has diminished, and there is emerging evidence that the attitudes and beliefs of all

youth (with and without disability) about sex and sexuality are being formed through media rather than formal education or parent and/or health care provider sources. This report aims to provide the pediatric health care provider with resources and tools for clinical practice to address the sexual development of children and youth with disabilities. The report emphasizes strategies to promote competence in achieving a healthy sexuality regardless of physical, cognitive, or socio-emotional limitations.

“Addressing sexual and reproductive health in adolescents and young adults with intellectual and developmental disabilities,” *Current Opinion in Pediatrics* (August 2018) [Link](#)

Abstract:

Purpose. This review provides support for promoting the sexual health of adolescents and young adults with developmental disabilities, and particularly those with intellectual disabilities. It offers guidance for pediatricians on incorporating counseling on sexuality and reproductive healthcare, socially appropriate behavior, and sexual abuse prevention for adolescents and young adults with developmental disabilities into healthcare visits. Additionally, it provides resources for developmentally appropriate sexuality education in the home and community to allow access to the comprehensive sexual and reproductive healthcare patients deserve.

Findings. Adolescents and young adults with developmental disabilities often do not receive developmentally appropriate sexual health education, and this is associated with poor sexual health outcomes and increased rates of sexual abuse in this population.

Summary. Pediatricians should discuss sexual health with all patients, including adolescents and young adults with developmental disabilities. They are well suited to provide sexual health education and inform families about appropriate sexual health resources.

“Sexual activity and sexual health among young adults with and without mild or moderate intellectual disability, *BMC Public Health* (May 2018) [Link](#)

Abstract:

Background. There is widespread concern about the sexual 'vulnerability' of young people with intellectual disabilities, but little evidence relating to sexual activity and sexual health.

Method. This paper describes a secondary analysis of the nationally representative longitudinal Next Steps study (formerly the Longitudinal Survey of Young People in England), investigating sexual activity and sexual health amongst young people with mild/moderate intellectual disabilities. This analysis investigated family socio-economic

position, young person socio-economic position, household composition, area deprivation, peer victimisation, friendships, sexual activity, unsafe sex, STIs, pregnancy outcomes and parenting.

Results. Most young people with mild/moderate intellectual disabilities have had sexual intercourse by age 19/20, although young women were less likely to have sex prior to 16 than their peers and both men and women with intellectual disabilities were more likely to have unsafe sex 50% or more of the time than their peers. Women with intellectual disabilities were likely to have been pregnant and more likely to be a mother.

Conclusion. Most young people with mild/moderate intellectual disabilities have sex and are more likely to have unsafe sex than their peers. Education and health services need to operate on the assumption that most young people with mild/moderate intellectual disabilities will have sex.

“Women with cerebral palsy: A qualitative study about their experiences with sexual and reproductive health education and services, *Journal of Pediatric Rehabilitation Medicine*, Vol. 14, No. 2 (2021) [Link](#)

Abstract:

Purpose. To explore the recalled experiences of women with CP regarding sexual health education and services they received.

Methods. Semi-structured interviews and focus groups were conducted at four academic tertiary hospitals with 33 adult women with CP. Templates were used to ask about four key content domains: appointment planning (including planning for a gynecologic exam), accessibility of services, experiences with providers, and recommendations for improvement. Sessions were transcribed verbatim and analyzed to generate a coding dictionary. Blinded coding was carried out for each transcript, with duplicate coding used to confirm identified themes. Iterative analysis was used to identify and consolidate coding and key themes.

Results. Similar barriers were discussed at the four sites, including lack of accessible exam tables, hospital staff unfamiliar with physical disabilities, and assumptions that women with CP are not sexually active. Many described the sexual education they received as brief, omitted, or mistimed. Self-advocacy was crucial, and recommended strategies ranged from pre-gynecologic exam medication to visit checklists.

Conclusion. Reproductive health education for young women with CP is frequently inadequate. Medical professionals lack relevant knowledge and awareness; medical facilities lack necessary infrastructure. Recommendations for improvements are made.

HCBS and Sexual Rights

“Sexual health in the community: Services for people with intellectual and developmental disabilities,” *Disability and Health Journal*, Nol. 10, No. 3 (July 2017) [Link](#)

Abstract:

Objective. This preliminary study analyzed national Medicaid HCBS waivers to determine how they provide sexuality services for people with IDD.

Methods. 111 FY 2015 HCBS 1915© waivers for people with IDD from 46 states and the District of Columbia were analyzed to determine which waivers were providing services related to sexuality. Expenditure and utilization data were analyzed to determine service allotment.

Results. Currently, less than 12% of waivers include any kind of sexuality services, and those services provided are predominantly reactive, rather than proactive. Reactive services focused on interrupting sexually inappropriate behaviors through assessments and plans, intervention and therapy, and supervision. Meanwhile, proactive services promoted the healthy sexuality of people with IDD by providing sexuality education related to sexuality awareness, reproduction, and victimization avoidance.

Conclusions. The limited availability of Medicaid HCBS sexuality service provision not only hints at a lack of understanding of sexuality for people with IDD, but also presents an opportunity to perform increased evaluations on current service offerings in order to justify future expanded offerings in other states.

“The Sexual Rights of Adults with Autism and Access to Sexuality Supports and Services,” New York City Autism Conference (2018) [Link](#)

Abstract: This presentation addressed the following issues: What Is Sexual Self-Advocacy? • Home and Community-Based Setting Rule and How It Can Impact Residents’ Sexual Rights And The Role of the Provider • OPWDD – Considerations Concerning Sexual Contact and Consent • Sexuality Services and HCBS Waivers • When Can Sexuality Services Be Limited or Restricted? • What If Resident Is Arbitrarily Denied Right to Express Sexuality or Receive Sexuality Supports?

Sexuality and Guardianships

“Equality and People with Mental Disabilities-The Issues, the Law, and the Guardian,” Training for Guardians, National Guardianship Association (2011) [Link](#)

Abstract:

Course Objectives. • The guardian will be able to recognize that people with disabilities are loving, sexual individuals who need, and have a right to enjoy human relationships. • The guardian will acquire knowledge about the issues relating to sexual matters and the role of the guardian in the decision making process for the individual. • The guardian will understand how their own attitudes toward sexuality may influence their professional decisions. • The guardian will examine the legal system as it applies to sexual activity and understand its applications. • The guardian will examine the fundamental rights and responsibilities which apply to people with disabilities and the people who provide them with support. • The guardian will be introduced to real-life situations dealing with sexuality and people with disabilities and will develop strategies for the education and protection of the wards they serve as guardian.

Learning Modules. Sexual Rights Of Persons With Disabilities Sexual Activity And The Law Of Consent • Constitutional, Criminal And Civil Law • Evaluation Of Competence In Making Choices And Decisions About Sexual Behavior • Clinical Determination Of Competency • Judicial Determination Of Competency • Surrogate Decision Making Vs. Voluntary Participation • Probate Court Decisions • Related Healthcare Issues • Policy For Professional Guardians • Sex Education And Guardianship Program Policy

“Sexual Expression for Adults with Disabilities: The Role of Guardianship,” Impact: Feature Issue on Sexuality and People with Intellectual, Developmental and Other Disabilities, University of Minnesota, Institute on Community Integration (Spring/Summer 2010) [Link](#)

Abstract: To what extent does or should having a guardian limit an adult's ability to fashion intimate relationships of his or her choosing? The answer for many people with disabilities is that, as a matter of law, guardianship need not limit the adult's right of sexual expression and conduct, but dialogue between the individual and his or her guardian can play a critical role in supporting the individual's decision-making in this area. This article explores issues that may arise in a guardianship.

Families and Care Providers

“Sexuality and Developmental Disabilities, North Dakota Statewide Developmental Disabilities Staff Training Program (June 2021) [Link](#)

Abstract: This training manual was developed by the North Dakota Center for Persons with Disabilities and is intended to be used for educational purposes by North Dakota community provider agencies participating in the Community Staff Training Project through Minot State University. This module is designed to provide you with the information and resources you

need to have necessary conversations and offer support to people who are learning about safe and healthy social/sexual behavior. Various resources, including articles, curricula, slides, videos and games that can be helpful are included in the appendix of this module.

“How can sexual and reproductive health and rights be enhanced for young people with intellectual disability? - focus group interviews with staff in Sweden,” *Reproductive Health* (June 2020) [Link](#)

Abstract:

Background. Different types of staff support individuals with intellectual disability (ID) in their daily life, in schools, leisure activities and in special accommodations. This study aimed to gain a deeper understanding of experiences and perceptions regarding sexual and reproductive health and rights (SRHR) among staff.

Methods. Data were collected in mid-Sweden in four focus groups with altogether 20 participants, 18 women and 2 men aged between 18 and 65 years. They had different professions and worked among youth and adults with ID aged 18-40 years in schools, accommodations and with leisure activities. Their working experience varied from 3 years to more than 20 years. Interviews were audio recorded, transcribed and analysed with content analysis.

Results. The participants generally described positive attitudes towards sexuality for people with ID, both among themselves and in society. However, many situations such as ensuring privacy, balancing between waiting and acting, issues around contraception and reproduction were difficult to address and participants had hesitations about childbearing. They described different strategies such as showing respect, enhancing self-esteem and decision making ability and using interprofessional support to cope with frustrating situations. They lacked a clear mandate from managers as well as written guidelines and policies. They requested education and support from peers, supervisors and other professionals.

Conclusion. Participants in the study were generally open-minded and accepting towards sexuality among young people with ID. They thought it was difficult to deal with reproduction/parenthood and felt unprepared and frustrated in certain situations. The participants requested a clear mandate from managers, organizational guidelines, more education and inter-professional support. We believe these findings can inform the development of policy and support the implementation of SRHR related guidelines to support staff working with young people with ID.

“The views and experiences of families and direct care support workers regarding the expression of sexuality by adults with intellectual disabilities: A narrative review of the international research evidence,” *Research in Developmental Disabilities*,” (July 2019) [Link](#)

Abstract:

Aims. The aim of this narrative review was to explore the views and experiences of families and direct care support workers in relation to the expression of sexuality by adults with intellectual disabilities and to identify their distinct support and development needs.

Methods. A comprehensive search of relevant databases from May 1998 to June 2018 was undertaken. Included studies had to address specific criteria: peer reviewed papers, the use of appropriate research methods, and focus exclusively on the individual views and opinions of families and direct care support workers. The search of relevant databases yielded 313 hits. Following the application of explicit inclusion and exclusion criteria, 11 papers were deemed suitable for the review. The PRISMA checklist was utilised in the process. Quality was assessed using a recognized framework.

Results: The data were analysed and key findings highlighted issues for families and direct care support workers including: attitudes and beliefs; fear of abuse, exploitation and harm; new technologies; supporting developments in practice; and education and training programmes.

Conclusions. Families and direct care support workers have specific support and education needs. Future healthcare initiatives need to be developed that are fully responsive to the identified concerns and requirements of families and direct care support workers.

“Transformed rights' sexual health programme evaluation for the parents and service workers of adults with an intellectual disability,” *Journal of Intellectual Disability Research* (September 2019) [Link](#)

Abstract:

Background. To promote sexual health in adults with an intellectual disability (ID) in Taiwan, sexual health programmes were provided to adults with ID, their parents and service workers. This study evaluates the impact of these programmes that involved the parents and service workers.

Methods. Intervention and participatory research paradigms were applied to develop, implement and evaluate programmes that address the challenges that relate to the sexual rights of adults with ID. Additionally, the programmes fostered open dialogue among the participants concerning the sexual health of people with ID. In total, 57 parents and 164 service workers were involved in the programmes. A quasi-experimental design and standardised questionnaires (Attitudes to Sexuality Questionnaire - Individuals with an Intellectual Disability), as well as in-depth interviews, were used to collect both quantitative and qualitative data on the programmes' effectiveness and participants' experiences between

April 2012 and July 2015.

Results. The findings revealed that after the programmes were implemented, attitudes towards the sexual rights of people with ID were significantly more positive among both the parents and service workers. Participation in the sexual health programmes facilitated constructive dialogue by revealing hidden concerns and by transforming the perspectives of the parents and service workers from viewing sexuality as a social problem to understanding the sexual rights of adults with ID.

Conclusions. Both the quantitative and qualitative results demonstrate that the programmes had a positive impact on the parents and service workers in terms of their attitudes towards the sexual rights of people with ID. Open dialogue and reciprocal interaction strategies caused transformations in the perspectives of parents and service workers on sexual health.

“Attitudes towards sexuality and related caregiver support of people with intellectual disabilities: A systematic review on the perspectives of people with intellectual disabilities,” Journal of Applied Research in Intellectual Disabilities (January 2022) [Link](#)

Abstract:

Background. Sexual health remains at risk for people with an intellectual disability. Attitudes towards sexuality, its support and education have an important role in promoting sexual health. The current review aims to provide an overview of the current research on supportive and restrictive attitudes towards sexuality and its support of people with intellectual disabilities themselves.

Method. A systematic review was conducted, searching across eight databases. The quality of the studies was assessed with the Mixed-Method Appraisal Tool.

Results. Six themes emerged from the data: sexual behaviour, sexual identity, intimate relationships, barriers to sexual expression, sex education and support by caregivers. Supportive and restrictive attitudes were reported throughout.

Conclusions. Attitudes regarding sexuality of people with intellectual disabilities are heterogeneous and people with intellectual disabilities seem to be able to express their sexual desires, needs and attitudes. Findings allow for improved individual support and in-depth research questions.

“Staff member's views and attitudes to supporting people with an Intellectual Disability: A multi-method investigation of intimate relationships and sexuality,” Journal of Applied Research in Intellectual Disability (July 2022) [Link](#)

Abstract:

Background. Staff member's views and attitudes can have a significant impact on people with an intellectual disability. This study explores staff attitudes and experiences of people with an intellectual disability's expression of relationships and sexuality across service providers in Ireland.

Methods. Staff (n = 86) from service providers (n = 5) completed the Attitudes to Sexuality Questionnaire-Individuals with an Intellectual Disability (ASQ-ID) and open-ended questions.

Results. Multidirectional significant differences were noted on staff attitudes to sexuality based on demographic factors, that is, age, education, as well as non-demographics, for example, attendance at training, and active practising of religion. Qualitatively, three themes emerged: "Unsupported and Frustration"; "Taboo Subject Matter" and "Vulnerability and Access to Education". Staff reported a lack of service supports, dominant conservative cultures and people with an intellectual disability's vulnerability.

Conclusion. This study highlights the need for improved service practices and enhanced provisions for staff and the people with an intellectual disability that they support.

“Sexuality and personal relationships for people with an intellectual disability. Part II: staff and family carer perspectives,” *Journal of Intellectual Disability Research* (November 2009) [Link](#)

Abstract:

Background. Recent ideological shifts in service provision promote appropriate sexual expression for people with an intellectual disability (ID), although there is little evidence that such advances in ideology are matched by current service provision. Part II of the current two-part study assessed the attitudes of staff and family carers to the sexuality of people with an ID.

Method. A questionnaire survey which included case scenarios was carried out with family (n = 155) and staff carers (n = 153) of people with an ID in the west of Ireland.

Results. In general, staff carers were more inclined than family carers to openly discuss issues of sexuality with service users, and to suggest environmental, rather than service-user characteristics, as impediments to such discussions. Attitudinal differences emerged with significant differences between staff and family carers and between younger and older carers. Staff carers were more likely to support service-user engagement in intimate and non-intimate relationships whereas the majority of family carers (80%) showed a preference

for low levels of intimacy in service-user relationships.

Conclusion. When compared with the attitudes of family carers towards the sexuality of people with ID, the attitudes of staff carers more closely match those promoted by ideological developments. However, differences in attitudes between carer groups may lead to inconsistent approaches to the management of sexuality. As a consequence, we conclude that there is continued need to provide staff and family carers with opportunities for dialogue and an ongoing need for training in the area of sexuality.

Community Attitudes

“Attitudes to Sexuality Questionnaire (Individuals with an Intellectual Disability): scale development and community norms,” *Journal of Intellectual and Developmental Disability* (September 2007) [Link](#)

Abstract:

Background. Attitudes to the sexual expression of adults with an intellectual disability (ID) are one reflection of the inclusiveness of a community. Our capacity to measure attitudes towards this important aspect of adult life is limited by the lack of an appropriate instrument. The aim of this study was to continue the development of a recently published questionnaire and to establish normative data.

Method. The Attitudes to Sexuality Questionnaire (Individuals with an Intellectual Disability) (ASQ-ID: Cuskelly & Bryde, 2004) was modified slightly and questions about hypothesised stereotypical views of sexuality were added. A community sample of 261 adults completed this modified questionnaire, as well as a shorter version of the questionnaire about attitudes to sexual expression in typically developing adults.

Results. Factor analysis revealed one general factor associated with sexual rights, plus three other factors related to parenting, non-reproductive sexual behaviour, and self-control. There were few differences in attitudes towards male and female sexuality, and attitudes were only slightly less positive for individuals with an ID than for those without a disability. Views about parenting by people with an ID were more cautious than for other aspects of sexuality.

Conclusions. The present study established the factor structure of an instrument for measuring attitudes towards the sexual expression of adults with an ID and provided normative data. Community attitudes towards the sexual rights of adults with an ID are generally quite positive.

“Intellectual disability and sexuality: attitudes of disability support staff and leisure industry employees,” *Journal of Intellectual and Developmental Disability* (March 2010) [Link](#)

Abstract:

Background. The attitudes of support staff and others in the community towards the sexuality of individuals with an intellectual disability (ID) have the potential to influence opportunities for normalised life experiences in the area of sexuality.

Method. 169 disability support staff and 50 employees from leisure and service industries completed the Attitudes to Sexuality Questionnaires (Individuals with an Intellectual Disability [ASQ-ID], and Individuals from the General Population [ASQ-GP]).

Results. Support staff and leisure workers reported generally positive attitudes towards the sexuality of individuals with an ID, but men were seen as having less self-control than women. Support staff were more cautious in their views about parenting, and both groups considered a lower level of sexual freedom to be desirable for women with an ID compared to women who are developing typically.

Conclusions. Attitudes of both groups are generally quite positive in relation to ID and sexuality.

Sexual Abuse

“Prevalence of Sexual Abuse in Adults with Intellectual Disability: Systematic Review and Meta-Analysis,” *International Journal of Environmental Research and Public Health* (February 2021) [Link](#)

Abstract: This study presents the results of a systematic review on the prevalence of sexual abuse experienced in adulthood by individuals with intellectual disability. An electronic and manual search of academic journals was performed on four databases via EBSCO Host: Academic Search Complete, PsycINFO, Medline, CINAHL Full-Text. In addition, PubMed, ProQuest, and Web of Science (core collection) were searched. After an initial selection of 1037 documents, 25 articles remained for quantitative synthesis. The combined prevalence of sexual abuse in adults with intellectual disability was 32.9% (95% CI: 22.7-43.0) and sensitivity analysis revealed that the prevalence was not outweighed by a single study. Overall, the United Kingdom had the highest prevalence (® = 34.1%), and the USA had the lowest (® = 15.2%). The overall prevalence in females was lower (® = 31.8%) than that in males (® = 39.9%). Subgroup analyses revealed that prevalence of sexual abuse was higher in institutionalized individuals. The most prevalent profile of abuser is of a peer with intellectual disability. Prevalence increases from mild to severe levels of intellectual disability and decreases in profound levels. It is also more prevalent when the informant is the individual with intellectual disability than when someone else reports abuse. In sum, one in three adults with intellectual disability suffers sexual abuse in adulthood. Special attention should be paid for early detection and intervention in high risk situations.

“Women with intellectual disabilities--a study of sexuality, sexual abuse and protection skills,” Australian Family Physician (April 2011) [Link](#)

Abstract:

Background. Sexual abuse and abusive relationships are known to be especially common in people with intellectual disability. This study explored how women with intellectual disability understand sex, relationships and sexual abuse, the effects of sexual abuse on their lives, and how successfully they protect themselves from abuse.

Methods. Semistructured narrative interviews with nine women with mild intellectual disability in Queensland, Australia. Interviews were audio recorded, transcribed, coded and analysed qualitatively.

Results. Major themes that emerged were: sexual knowledge and sources of knowledge; negotiating sexual relationships; declining unwanted sexual contact; self protection strategies; sexual abuse experiences; and sequelae of sexual abuse.

Discussion. Most participants reported unwanted or abusive sexual experiences. They described sequelae such as difficulties with sex and relationships, and anxiety and depression. They described themselves as having inadequate self protection skills and difficulty reporting abuse and obtaining appropriate support. Their understanding of sex was limited and they lacked the literacy and other skills to seek information independently. It is important for general practitioners to be aware of the possibility of sexual abuse against women with intellectual disability, and to offer appropriate interventions.

“Disability and Abuse: Administering Trauma-Informed Justice in Missouri Guardianship Proceedings,” Annotated Bibliography with Strategic Commentary, Spectrum Institute (2017) [Link](#)

Abstract:

This bibliography is the foundation for the presentation of Thomas F. Coleman at the 4th Annual Educational Summit sponsored by The Arc of Missouri. It references articles and report on the following topics: disability demographics in Missouri; prevalence of abuse; mandatory reporters of abuse; supported decision-making; rules of professional conduct for attorneys; Americans with Disabilities Act.

“Clarifying Data on Disability and Crime Victimization,” Spectrum Institute (2020) [Link](#)

Abstract: This commentary clarifies information in a story about sexual assault of people

with disabilities produced by National Public Radio. It is intended for distribution to researchers, protective service workers, law enforcement agencies, advocates, mental health professionals, guardians, conservators, and service providers. What NPR told its audience is generally correct. Vulnerable populations have higher rates of crime victimization. But educators and advocates speaking about disability rates should be more precise.

“Abuse of People with Disabilities: Victims and Their Families Speak Out.” Report on the 2012 Survey on Abuse of People with Disabilities, Spectrum Institute (2013) [Link](#)

Abstract: The report summarizes the findings of the largest survey on abuse of people with disabilities ever done in the United States. Some 7,289 people took the online survey. Most of the respondents had a direct connection with the disability experience, either having a disability (20.2%) or having an immediate family member with a disability (47.4%). Some 41.6% reported that they or a loved one with a disability experienced sexual abuse. The rate of sexual abuse varied greatly depending on the type of disabilities they had. Some 47.4% of people with mental health conditions had been victims of sexual abuse, whereas 34.2% of those with intellectual or developmental disabilities, 31.6% of those with a mobility disability, and 24.9% of those with autism reported they had experienced sexual abuse.

Capacity to Consent to Sex: Legal Standards & Best Practices for Adult Protective Services, Spectrum Institute (2020) [Link](#)

Abstract:

Knowing the law on capacity, using best practices for assessments, and complying with mandates of the Americans with Disabilities Act, are essential to effective APS investigations, referrals, and social services.

The legal criteria for capacity to consent to sex vary considerably from state to state. The areas of inquiry during a clinical assessment process must match the legal criteria for capacity. The law is the driving force and foundation for an assessment of capacity. Because criteria vary with each state, there can be no uniform protocol throughout the nation for the types of questions that are asked or the areas of an individual’s knowledge that are probed. An assessment professional must learn the legal criteria in the jurisdiction where the assessment is being done and use those criteria to guide the assessment process.

Inquiries into subjects that are not relevant in a particular state would be unnecessarily intrusive, discriminatory, and probably illegal. For example, in several states an individual does not need to know or understand risks or consequences of various types of sex. Nor is there a requirement for the person to understand proper places for sex to occur. Asking questions about such matters in those states would be a form of discrimination against people with disabilities. In other states, an individual must not only know about consequences but also must understand the moral implications of their behavior. In those states, until the law

is changed to remove this consideration, any assessment that does not probe into an understanding moral consequences would be legally deficient.

However, there are areas where uniformity in all states is possible: (1) assessing an individual's understanding of voluntariness, including the ability to resist pressure and to comply when another person says no; (2) the need for assessment professionals to follow the mandates of the Americans with Disabilities Act in the assessment process; and (3) the use of best practices for interviewing people with disabilities.

This report is intended to help APS professionals gain a better understanding of the complexities of assessing capacity to consent to sex so they can provide a proper balance between respecting the freedom of, and providing protection to, their clients.

Abuse Awareness and Prevention Guide, State of Missouri - [Link](#)

Abstract:

The Charting the LifeCourse: Abuse Awareness and Prevention Guide is intended for self-advocates and families, and professionals who might interact with or provide support to a self-advocate. It is focused on the topic of abuse to people with disabilities. The purpose of this guide is to provide: information on what abuse is, what are the types and signs of abuse, and what to do if abuse happens; tools for thinking and planning about how to stay safe prior to or after an abuse; and additional resources for seeking help and support after an abuse has occurred.

In this document, self-advocate refers to individuals with disabilities. This guide interchangeably uses the terms “self-advocate” and “person with a disability.” The term “survivor” is sometimes used to refer to a person who has been abused. "Supporter" refers to any person working through the guide with a self-advocate including a family member, a friend, paid support staff, support coordinator or a survivor advocate.

This guide is designed to be used by a self-advocate “side-by-side” with a supporter. There are sections titled “supporter” throughout the guide that provide additional ideas for discussion and considerations for how the support person can best facilitate and reinforce the information learned.