



Autism and Adult Sex Education: A Literature Review Using the Information–Motivation–Behavioral Skills Framework

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Abstract

Adults on the autism spectrum report comparable levels of desire for sex and sexual satisfaction as adults who are not on the spectrum. However, there has been little empirical focus on the need for sexual and relationship-oriented education for youth on the spectrum as they transition to adulthood. In this review, we use the Information–Motivation–Behavioral Skills Model of sexual health behavior change as a lens through which to understand the experiences of adults on the autism spectrum. We present those insights infused with emerging data and best practices in the field. Overall, it appears clear from the extant literature that providers need to recognize the specific characteristics of autism when developing sexual education curricula. Specifically, the social communication and sensory profile of people on the autism spectrum appears to interact with access to information, motivation to engage in healthy sexual activities, and the development of skills needed to engage in healthy sexual behavior. Finally, the voice of adults on the spectrum is essential to guide the emerging understanding of healthy sexuality.

Keywords Autism · Sexuality · Sex education · Sexual health · Romantic relationships · United States

As individuals on the autism spectrum reach adulthood, they experience a unique set of challenges related to sexual health, dating, and romantic relationships. However, there has been little attention paid to the need for sexual and relationship-oriented education

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for youth on the spectrum during this transitional period between adolescence and adulthood. Although the Individuals with Disabilities Education Act (IDEA) requires the development of a transition plan for high school students once they reach the age of 16, such plans generally focus exclusively on vocational training, independent living, and housing [1]. Although those goals are all important for the future trajectory of adults on the autism spectrum, social skills are often listed as secondary goals, and then only in the context of gaining and maintaining employment. Instruction in skills related to hygiene, dating, sexuality, and sexual behavior are rarely mentioned. The critical need for individualized educational plans between adolescence and adulthood to include a provision for sex education has been described by a number of autism specialists [2–6] as well as individuals on the autism spectrum [7–9].

In conceptualizing sexual education needs of adults on the autism spectrum, the Information–Motivation–Behavioral Skills (IMB) Model [10, 11] provides a potentially useful framework. The IMB model has been applied to a number of populations, primarily in the area of reducing sexual risk behaviors and preventing the spread of HIV [12]. The model is powerful in its simplicity. The IMB model comprises three distinct constructs: accurate knowledge, high motivation, and having in one's repertoire the requisite behavioral skills to interact interdependently to predict the likelihood of an individual engaging in adaptive/healthy (vs. maladaptive/risky) sexual behaviors. There is a long history of strong empirical support for the IMB model in the field of behavioral medicine, especially in terms of reducing sexual risk behavior. For example, in addition to predicting the use of condoms for penetrative sex, IMB model constructs have predicted sexual health relevant cognitions, such as risk appraisals of sexual encounters [13]. A few recent studies have begun to investigate the use of the IMB model to understand the health behaviors of people on the spectrum (e.g., a study of online dating [14]). There has been one published study examining the IMB model to study parent adherence to behavioral intervention for children with a diagnosis of an autism spectrum disorder [15]; however, we could not identify in the published literature any intervention development efforts using the IMB model that target dating and sexual health with individuals on the spectrum. Thus, in the present paper, we outline approaches to sexual education for adults on the autism spectrum with attention to the IMB model.

By using the IMB model, we aim to inform best practices and implement effective interventions targeting the unique set of needs of adults on the autism spectrum with regard to safe sex practices and healthy romantic relationships. The questions guiding our thinking in the present paper include: How are people on the autism spectrum receiving information about sex education and romantic relationships? How do the sources of that information, as well as the content, differ from that to which their typically developing peers are exposed? What is the level of motivation for adults on the autism spectrum to develop romantic relationships and engage in solo or partnered sexual behavior? Conversely, what are some barriers that may be inhibiting adults on the autism spectrum from participating in dating and sexual and or romantic relationships? Finally, we aim to examine current preferences with regard to sexual activity and romantic relationships among adults on the autism spectrum. We examine the current literature as well as several voices from adults on the autism spectrum to outline the current understanding of these topics.

Information

Currently, the literature suggests that adults on the autism spectrum acquire knowledge about sex and romantic relationships from different sources than their peers without autism. Adults on the spectrum were less likely to report learning about sexually transmitted diseases, contraceptives, and sexual behaviors from social sources, such as parents, teachers, and peers, as would be expected for non-ASD individuals (e.g., [16]). First, some parents and health care providers feel hesitant to discuss sexuality [17–21]. This may be due to a fear that such discussions will increase interest in or likelihood of sexual behaviors, lack of confidence in their own ability to teach sexual content, or the misperception that individuals on the autism spectrum are unmotivated to have romantic or sexual partnerships [21, 22]. In one quantitative study, which enrolled 43 parents of Dutch or Belgian cultural backgrounds who had sons aged 15–18 on the autism spectrum, participants completed nine self-report questions designed for that specific study [23]. Results indicated that parents underestimated the sexual experiences of their adolescent sons [23]. Parents also omitted key information when discussing with their children on the spectrum (a) romantic relationships, (b) sexual health and prevention, and (c) sexual activities other than intercourse [16, 18]. For instance, only 50% of parents discussed how to decline unwanted sex, 40% discussed not pressuring others to have sex, and 20% discussed correct condom use [24]. Additional barriers to providing comprehensive sexuality-related care to youth on the autism spectrum included logistics, parent discomfort, and lack of appropriate materials [20]. Similarly, more than half of healthcare providers viewed their lack of training and access to accurate information as an obstacle to providing information about sexual health to patients on the spectrum [20, 25]. Adults on the spectrum and their parents universally also reported dissatisfaction with school-based sex education and a need for autism-specific instruction [7, 26, 27]. These adults on the spectrum who reported challenges with sex-education also reported lower sexual knowledge and assertiveness and difficulty understanding and adapting information aimed at peers who are not on the spectrum [7, 26].

Additionally, people on the autism spectrum who have communication difficulties, or those who have difficulty fitting in socially, may have fewer opportunities for learning sexual information from peers. Instead, these individuals may obtain sexual information from less accurate sources including the internet, pornography, movies, television, educational materials, and learn from past failed social experiences [16, 28]. As reported in the Pecora et al. [28] study on women on the autism spectrum, media outlets are utilized the most for sexual knowledge [29]. These media sources, including television and movies, can be misinterpreted as evidence of accurate social scripts affirmatively indicating behaviors to engage in when pursuing relationships. Taken together, these sources are potentially inaccurate and are not personalized to each individual on the spectrum.

Motivation

An anonymous survey of adults on the autism spectrum across several nations revealed that their sexual desire and satisfaction was generally equivalent to the published data for adults without autism [18]. Despite the profile being similar, Hénault and Attwood [18] reported that people on the spectrum generally have fewer opportunities to engage in sexual relationships due to poor social communication or being in an environment that limits their

ability to meet sexual partners. Atwood's seminal work in this area was recently replicated [30] in a survey of boys and men aged 12–25 years who were both on and off the spectrum. Comparable percentages of boys in both groups reported having engaged in a variety of sexual experiences, including partnered and solo sexual encounters. Thus, individuals on the autism spectrum report a normal interest and desire for sexuality, [31, 32] and similar age of debut for sexual thoughts and behaviors [33], lending support to the notion that adolescents and adults on and off the spectrum have similar sex education needs.

Despite an emerging literature which demonstrates that people on the autism spectrum are motivated to engage in romantic relationships and sex, they struggle with expressing and interpreting the intentions of others. These difficulties are consistent with the features of autism [34]. Specifically, in Pecora et al.'s [28] systematic review of sexuality and autism, they identified that women with autism seek information from less reliable sources of information, including television and soap operas, which are limited in terms of providing valid sexual knowledge and effective social scripts. Limited peer interactions and relationships further impact the ability to obtain and practice functional social and sexual behaviors. Therefore, individuals on the spectrum may miss out on potential opportunities for forming relationships and engaging in functional sexual behaviors despite a motivation for both.

Additional barriers to forming romantic relationships and engaging in functional sexual behaviors can include social emotional factors such as increased anxiety, peer rejection, frustration, and isolation. Across studies, both adults on the autism spectrum and their caregivers report increased difficulty adjusting to the demands and changes that occur with puberty, with increased risk for anxiety and distress particularly among women on the autism spectrum [28]. In addition, as social demands in adolescence continue to become more complex, people on the autism spectrum are likely to face challenges meeting those social demands. Based on a review of clinical accounts, although there is a strong interest in participating in social relationships, there is a concomitant feeling of not fitting in and feeling rejected by peers, particularly among women on the autism spectrum [28]. Thus, although sexual interest and desires emerge at the same time as typically developing peers, barriers including increased anxiety with regard to puberty and decreased exposure to appropriate social relationships leads to greater levels of social isolation and frustration.

Behavioral Skills

One of the fundamental challenges people on the autism spectrum face is behaving in ways that are considered socially acceptable [35]. Difficulties interpreting socioemotional situations can also result in individuals on the spectrum engaging in behaviors that do not lead to their intended outcome. As an example, Attwood [36] provided a case discussion of a male client who continued to purchase gifts for a girlfriend after they had broken up. When the client was asked how he thought his ex-girlfriend was feeling, the client replied he thought she was feeling sad about their break up, and so he bought her gifts as a way to cheer her up. The individual was not incorrect that his former girlfriend was upset (so he was not misreading the situation *per se*), however, he was not following subtler and less defined social rules about post-breakup behavior. Such misinterpretations of social expectations likely put people with autism at a disadvantage when it comes to forming and maintaining relationships, as well as negotiating sexual encounters—the latter of which often rely heavily on non-verbal communication. Indeed, maladaptive sexual behavior was

reported for about a quarter of adults on the spectrum, with higher rates found for adults without intellectual disability [37]. For example, adults on the spectrum are more likely to engage in socially maladaptive or illegal dating behaviors (e.g., becoming obsessed, stalking), and use less functional partner selection (e.g., celebrities) strategies than their peers [38].

The Need for Autism-Specific Sexual Education

One emerging theme in the literature that is echoed in conversations with people on the autism spectrum, their family members, and service providers is that individuals who meet criteria for ASD possess a unique set of needs related to dating, romantic relationships, and sexual health. Yet, these needs have only recently begun to be chronicled. Critically, emerging literature demonstrates that social ability predicts romantic and sexual functioning in adults on the autism spectrum [38, 39] as well as parental perceptions and provision of sexual information [27, 40].

To date, based on a review of the published literature, it appears that sexual education curricula are only beginning to be developed for people on the autism spectrum. To that end, we could identify only one curriculum designed for adolescents on the autism spectrum [41, 42]. Existing programs for individuals with developmental disabilities more broadly [43, 44], and evidence-based dating and sexuality skills interventions for adolescents without ASD [45–47], may provide a starting point for adaptation. However, the social communication difficulties that are a hallmark of autism spectrum disorder [34]—which can lead to fewer social relationships and a reduced ability to understand the complex information conveyed by others—likely impact the ability of adults on the autism spectrum to engage in functional romantic and sexual relationships across all levels of the IMB framework. Thus, we argue that consideration of ASD-specific needs is critical to developing interventions that are successfully implemented with people on the spectrum and outline several ASD-specific features as they impact IMB outcomes.

One challenge for many people on the autism spectrum is theory of mind, or perspective taking, which may decrease the likelihood of surmising that others' knowledge and experiences are different than their own [48, 49]. Related to this ability, people on the spectrum often do not interpret subtle body language and nonverbal cues. Individuals with ASD may require more concrete and transparent cues to hold an accurate awareness of another person's emotional state. As a result, the behavior of individuals on the spectrum may be less adaptive, as they may be unlikely to elicit information from others about their intent (kissing vs. intercourse), potentially leading to unwanted sex on the part of either partner, or about a partner's use of contraception or their sexually transmitted infection (STI) status. Difficulty with perspective taking can also lead to misinterpretation of body language, and result in expressing too much or too little affection in response to others [50]. In sexual interactions, another notable difficulty with social understanding is a reduced ability to predict others' trustworthiness [51], which has clear implications for partner selection behavior and, potentially, victimization.

Second, people on the autism spectrum often experience difficulties with pragmatic (i.e., social use of) language [34, 52]. Potential behavioral consequences of reduced pragmatic language would include difficulty raising conversations about sensitive topics like sexuality, failure to recognize from indirect pragmatic cues that intimate topics or declarations of dating/sexual interest are unwelcome, or using casual or slang sexual terms in

inappropriate situations. Indeed, adults on the spectrum identified the need to be explicitly taught “dirty talk” [7]. Pragmatic language challenges may also impact the knowledge of adults on the spectrum. Indirect or nonliteral language may limit the benefit of explanations in school-based sex education and reduced pragmatic skills may make it difficult for adults on the spectrum to determine whether sexual content is being relayed for instruction versus humor.

The difference in the sensory experience of physical contact represents a unique challenge for people on the spectrum. As such, showing love and affection can be a challenge because the sensory experience can feel uncomfortable (i.e., like too much pressure), which can lead people on the spectrum to learn to hide their feelings in order to avoid physical contact [50]. Alternatively, some people on the spectrum crave contact due to the deep pressure sensation but may not associate the behavior with affection or love [50]. Thus, beyond social communication symptoms, people on the autism spectrum likely experience unique factors that impact their behavior and need for knowledge such as explicit instruction about the connection between physical contact and love and affection.

Difficulty with social thinking, potential sensory sensitivities, as well as reduced knowledge or inaccurate information, combined with a demonstrated interest in sexual interactions [31, 32], appear to put many people on the spectrum, who may be more naïve in the context of romantic social interactions, at risk for poor sexual health [53]. Worse yet, this combination of low knowledge, reduced benefit and access to sexual education, and enduring interest may increase their likelihood for victimization, a fear which has been substantiated by research. In a sample of nearly 100 adults on the autism spectrum (compared to their peers without autism), rates of unwanted sexual contact were 3 times higher, sexual coercion was 2.7 times higher, and rape was 2.4 times higher [17]. Sexual knowledge was significantly lower in the same group with ASD than the comparison group and sexual victimization was associated with reduced knowledge for adults on the autism spectrum [17].

Representing the Voice of People on the Autism Spectrum in Sex Education

In addition to empirical findings and data gathered from experts in the field, it is crucial to consider the opinions and experiences of people on the autism spectrum expressed directly by them and in their own words. In this section, we review the perspectives and recommendations of several prominent adults on the spectrum, who offer insights into the unique challenges and strengths of people on the spectrum surrounding dating, relationships, and sexual health. Consistent with emerging research and the best clinical practices described above, these individuals echo the need to present information in a straightforward, factual manner that employs the use of visuals, and one that involves both teaching and strengthening social skills.

McIlwee Myers [54], a married woman on the spectrum, wrote a first-person account of dating and marriage. In this testimonial, she encourages people on the spectrum to consider questions such as whether they want to date now, later, or ever; whether they intend to marry; and, whether they want to share a house with someone who wants things to be different, such as cooking foods they dislike, sharing space, etc. Myers noted that meeting potential partners in clubs or noisy bars is challenging because of common sensory sensitivities. Myers highlights the difficulty of being rejected by a romantic interest for

people on the spectrum and the difficulty of trying to meet social expectations of a ‘standard model’ when meeting partners [54, p. 98].

Similar to the experiences of neurotypically developing adults, there are a wide variety of preferences about sexuality and sexual behavior among adults with autism. However, there is a growing literature that documents the prevalence of romantic and sexual feelings for the same gender appears to be higher among adults on the autism spectrum than in the general population [32, 39, 55–57]. Sexual and gender identities are also more fluid for adults on the autism spectrum [58, 59].

For some people on the autism spectrum, acceptance of having no desire to date is also important. Instead, being single, happy, and independent is preferable. Temple Grandin, an animal science professor, author, and woman on the autism spectrum, chooses to be celibate [60]. She derives meaning and happiness from her career and projects. Grandin writes, “some people with autism want to get married and others don’t and both are completely alright” [60, p. 150].

Implications for Intervention

Information

Despite the fears of many parents and providers that discussing sex and dating will lead to more sexualized behavior or preoccupations, existing data indicate that there is no significant association between knowledge of sex and higher interest in sexuality of adults on the spectrum [61]. Rather, lack of sex education was associated with more anxiety and reduced ability to make accurate judgments in dating and sexual contexts. Similarly, people on the spectrum who are well informed about sex and sexual risk reduction practices tend to have a later age of sexual debut [53].

Although researchers advocate for sex education for people on the spectrum, educational materials about sexuality developed for youth *without* autism often lack enough specific detail and fact-oriented structure for people on the spectrum [53]. Best practices when teaching and or creating a curriculum focusing on social thinking, romantic relationships, and sex education include keeping explanations short and factual, using brief yet specific and concrete language, presenting information visually such as using videos, involving parents, and emphasizing problem solving and role play [2, 62, 63]. Additional recommendations include providing education outside the regular education classroom, using concrete teaching materials such as anatomically correct dolls, and frequently reviewing and reinforcing the material [2]. Finally, the context of the instruction is a critical factor. Creating an environment where there are peer-initiated interactions and conversations is important for increasing opportunities to share and learn from experiences in a social context [62]. Likewise, behavioral training for sexual abuse prevention skills of women with an intellectual disability led to skills acquisition, but generalization of skills did not occur in the community, whereas training delivered in the actual environment or with more realistic role play supported increased generalization and ability to demonstrate skills in the community [64].

A growing literature identifies a number of critical content areas for people on the spectrum [2, 5, 6, 53, 62, 65, 66]. Specifically, topics aimed to increase skillful behavior and self-confidence, manage opportunity, and decrease risky behaviors include: privacy awareness, the ability to non-comply, and understanding personal rights [62]. Knowledge

of what kinds of interactions are and are not expected increases the likelihood of being assertive in protecting one's own body and in reporting violations [2]. As a foundation, sexual health curricula should also include information about anatomy, puberty, personal care and hygiene, medical examinations, contraception, and the "rights and responsibilities of sexual behavior" [2, p. 401]. Content related to social aspects of sexuality and sexual expression include: differences between a friend and a dating partner, public versus private behaviors, consensual touching, and what constitutes sexual abuse [65]. These researchers emphasize the importance of a modified sex education curriculum for the specific needs of learners to promote safety, independence, and the ability to make informed decisions that promote sexual health and safety.

Women on the autism spectrum also require education about their need to receive gynecological care and their unique needs with respect to reproductive and sexual health [65], including menstruation and gynecological exams and optional accommodations that could be made. In addition, education about the menstrual cycle is also important as is information about how to use a tampon or sanitary pad [67]. Information aimed at women on the spectrum regarding sexual health rights and benefits not only educates women, but may aid in decreasing their anxiety, help to prevent sexual abuse or illness, and empower women to be responsible for their own sexual health. A pilot study following three women on the autism spectrum found that using social stories to explain menstrual care was effective at increasing knowledge about reproductive development and independently managing menses [68].

There are certain topics that seem important to include when working with adults with a more severe expression of autism. These include, for example, distinguishing public versus private sexual behavior, including communication about public touching and masturbation. Explicit instruction should be provided regarding the kinds of touching that may be used in public, with family and friends, and with a significant other—along with thorough, concrete, and simple explanations of where and how to touch or not touch other people [53]. Instruction about which body parts are considered private is also critical.

Motivation

In teaching people on the autism spectrum about sex, maintaining a positive approach without fear or shame is important to enable development of healthy attitudes about sex [53]. Presenting sex education in a way that is understandable is also crucial because those who are well informed have more "confidence to negotiate effectively with a partner" and to engage in sexual practices that minimize the risk of STIs or unwanted pregnancy when they do become sexually active [53, p. 19]. In addition to facts, it is important to address feelings that arise when teaching sex education. Uneven development of emotional functioning of youth on the spectrum relative to the onset of puberty and hormonal changes may result in sexual desires that may not be expressed using the conventions understood by people without autism [50].

Cognitive behavioral therapy (CBT) is an evidenced based system of psychotherapy which focuses on how thoughts influence behaviors and emotions and has been utilized in the treatment of anxiety related conditions in ASD [69]. Several pioneering researchers and clinicians who focus on romantic relationships for people on the autism spectrum have successfully implemented CBT techniques when teaching core concepts about relationships. Attwood focused on strengthening understanding of love and affection. In this application of CBT, which capitalizes on the logical thinking associated with autism, people with

autism are “scientists in the exploration of love and how to express it” [50, p. 272]. CBT techniques, including using a “love thermometer” to systematically measure increments of love, have been used to teach how the strength of love might differ across circumstances (e.g., *liking* vs. *loving*). Using concrete CBT techniques and strategies can be a motivating and engaging way for people on the autism spectrum to learn.

Another study examined whether a CBT group focusing on love and affection would increase participants’ ability to effectively display the social behaviors indicative of love and affection [70]. The therapy focused on rating levels of love and affection for various situations, social stories illustrating “how liking or loving someone can affect thoughts and behaviors,” and learning how to give and receive compliments [70, p. 2]. After the program, participants were significantly better able to display love and affection through physical and verbal means. However, participants’ abilities to receive love and affection from others remained unchanged. Thus, CBT may be effective in aiding people on the spectrum to form romantic relationships via better understanding of abstract concepts such as love, learning and practicing dating behaviors that are aligned with their level of motivation, and expressing their feelings of love and affection more accurately.

Behavior

Difficulties interpreting socioemotional situations can result in behaviors that do not lead to the intended outcome for adults on the spectrum. Misinterpretations and miscommunications also likely put people with autism at a disadvantage when it comes to forming and maintaining relationships. To address gaps in skillful sexual and dating behavior for adults on the autism spectrum, the strategies employed in social thinking may be useful. Garcia Winner has broken down social thinking into four steps that occur before, during, and after social interactions [35]. In the first step of sharing a space with another person, social partners must think about one another. Second, both social partners consider the intentions of the other. Third, both have thoughts about the other person and wonder what the other person thinks of them. Lastly, each partner monitors and potentially modifies their own behavior to increase the likelihood of being viewed desirably. Even at its most basic level—negotiation of physical space with a potential partner—the social thinking framework has clear implications for sexual encounters. Specifically, developing skills to navigate physical proximity in a sexual interaction provides a foundation for a sex education curriculum that addresses consent as well as healthy and enjoyable sexual encounters. Further, adults on the autism spectrum benefit from explicit instruction for reading nonverbal cues such as touch and eye contact and from establishing a vocabulary and the ability to verbally express interest in (or decline) sexual encounters. Additionally, youth on the spectrum need specialized information about social boundaries so they do not engage in unwelcome sexual behaviors [53].

Behavioral techniques such as imitation, modeling, and role play should be used, repeated, and practiced in real-life settings [62]. To facilitate this skills enhancement, delivery of sex education in a therapeutic group setting or individual counseling coupled with social skills training is recommended [62]. When issues such as public masturbation do arise, service providers may develop a behavioral plan that includes interrupting the behavior, redirection, and reminders of the acceptable place for the behavior [62]. As a preventative measure, behavioral reinforcement for staying in assigned areas and taking breaks as scheduled decreases the likelihood of attempts to masturbate at

unacceptable times. Curricula may include providing “visual evidence of scheduled breaks or private leisure time, so the person can anticipate and plan for personal needs” [62, pp. 128–129].

Future Directions

Promoting education and skills development about dating and sex leads to better informed decisions, a greater sense of identity and autonomy, and a decrease in sexual abuse [62]. Sex is more than just intercourse; it encompasses “gender-role socialization, physical maturation and body image, social relationships, and future social aspirations” [2, p. 398]. Yet, Murphy and Elias [2] and Koller [62] also note that sex education for people with disabilities is often limited by societal and social misconceptions surrounding sexuality of those with disabilities, which may be more of a hindrance than the disability itself. No matter their level of interest in dating, relationships, and sex, it is critical that adults on the spectrum receive education to help effectively communicate their needs and desires, to understand accurately how their bodies work, to know their rights, and to have access to available resources for sexual and reproductive health.

In conclusion, sexual health—including and the ability to navigate the romantic social encounters that underlie sexuality—represents an exciting and crucial opportunity for collaborative work between adults on the autism spectrum, health care providers, and researchers. As outlined above, the IMB framework provides a useful heuristic for organizing the emerging literature and conceptualizing the development of sexual health for adults on the autism spectrum. Critically, adults on the autism spectrum represent a population with a highly unique set of social and sensory needs, and these autism-specific factors likely impact the acquisition of knowledge, the motivation to engage in various romantic behaviors, and the acquisition of skillful sexual behaviors. This theme is echoed throughout the current clinical practices and from the voices of adults on the autism spectrum. Taken together, this foundation of best practices and emerging research provide a launching point for the development of sex education curricula that will empower adults on the autism spectrum to enjoy and participate in healthy sexual behaviors.

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Compliance with Ethical Standards

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